DOCUMENT RESUME

ED 224 204 EC 150 386

AUTHOR	Reynolds, Grace D., Ed.
TITLE	Proceedings from Mainstreaming Activities for Youth (Project MAY). Congresses and Conferences (New York, New York, September 10-12, 1981).
INSTITUTION	National Board of Young Men's Christian Associations, Longview, Wash.
SPONS AGENCY	Office of Special Education and Rehabilitative Services (ED), Washington, DC.
PUB DATE	81
NOTE	388p.; Print may be variable due to condition of original.
PUB TYPE	Collected Works - Conference Proceedings (021)
EDRS PRICE	MF01/PC16 Plus Postage.
DESCRIPTORS	Agency Cooperation; Community Resources; *Disabilities; Elementary Secondary Education; Foreign Countries; *Mainstreaming; Models; Parent Attitudes; Physical Fitness; *Recreational Activities; Volunteers; *Youth Agencies

ABSTRACT

The document contains 1981 proceedings from Project MAY (Mainstreaming Activities for Youth), a collaborative inservice training project involving 11 national agencies serving youth and invited resource organizations. Three project goals are listed--to develop cooperation and share hearings in meeting the needs of handicapped persons, to provide inservice training to multiagency leadership in developing programs for the handicapped, and to develop materials for use within voluntary organizations serving youth. Papers are presented from Project May Congresses held in New York City, Honolulu (Hawaii), Dallas/Fort Worth (Texas), Chicago (Illinois), and Livonia (Michigan). Entries cover the following topics: an international overview of the state of the art of services and programs for the handicapped, cultural universals in mainstreaming, coordination of resources and funding, development and coordination of community resources tools for mainstreaming, youth club work, camping, model systems for mainstreaming, health and fitness, older adults, volunteerism, parents' viewpoints, and adaptive aquatics. Also provided are conference agendas, lists of participants, opening and closing conference remarks, and keynote addresses. (SW)

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PROCEEDINGS

from

Mainstreaming Activities for Youth
(Project MAY)

Congresses and Conferences

1981

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Project Officer
William A. Hillman, Jr.

Project Director
Grace D. Reynolds, Editor

MAINSTREAMING ACTIVITIES FOR YOUTH

(Project MAY)

A special project of the National Board of YMCA's
Program Development Division
funded by the United States Department of Education
Office of Special Education and Rehabilitative Services,
Office of Special Education
to assist national youth serving agencies in
planning, developing, implementing, promoting and evaluating
a collaborative program to mainstream youth
with disabilities in regular programs.

*Note: The following material was transcribed from actual tape-recordings of the meetings. Unfortunately, some sections were not audible and we were unable to provide the material.

1979-1982

Mainstreaming Activities For Youth

PROJECT MAY SUPPORT GROUPS

Aloha Council for the Blind, Honolulu, Hawaii
American Alliance for Health, Physical Education, Recreation & Dance, Reston, Virginia
American National Red Cross, New York City
American National Red Cross - Youth Services, Washington, D. C.
Association for the Support of Human Services, Westfield, Massachusetts
Atlantic Richfield Foundation, Los Angeles, California
Boys' Clubs of America, New York, N. Y.
Boy Scouts of America, Dallas, Texas
Camp Fire, Inc., Kansas City, Missouri
Center for Independence of the Disabled, New York, N. Y.
Civitan International, Honolulu, Hawaii
Council for National Cooperation in Aquatics, Manassas, Virginia
County Council Board for Mentally Handicapped, Gothenburg, Sweden
Croydon YMCA, England
Deaf Action Group, Honolulu, Hawaii
Department of Education, State of Hawaii, Honolulu, Hawaii
Department of Health, Honolulu, Hawaii
Department of Parks and Recreation, Honolulu, Hawaii
Easter Seal Society for Crippled Children and Adults, Chicago, Illinois
Easter Seal Society of Honolulu, Hawaii
Eastern Queen Branch YMCA, New York, N. Y.
Edmonton YMCA, Edmonton, Canada
Exxon Corporation Foundation, New York, N. Y.
Friendship Facilities, Ottawa, Illinois
Future Homemakers of America, Washington, D. C.
George Mason University, Fairfax, Virginia
George Williams College, Downers Grove, Illinois
Girls Clubs of America, New York, N. Y.
Girl Scouts of the U.S.A., New York, N. Y.
Goodwill Industries of America, Washington, D. C. and New York City
Greater New York Metropolitan Board YMCA, New York, N. Y.
Hawkins and Associates, Inc., Washington, D. C.
The Healing Community, White Plains, New York
Hiroshima YMCA, Japan
International Council on Health, Physical Education and Recreation, Washington, D. C.
International Council of Sports and Physical Education, London, England
International Paper Company Foundation, New York, N. Y.
International Year of Disabled Persons, Washington, D. C., New York City and Honolulu
Jewish Federation, New York City, N. Y.
Jewish Welfare Board, New York, N. Y.
Joseph Bulova School, Woodside, New York
Joseph P. Kennedy, Jr. Foundation and Special Olympics, Washington, D. C.
The Kids Project: New York State Office of Mental Retardation and Developmental Disabilities, Albany, N. Y. and New York, N. Y.
Kuala Lumpur YMCA, Malaysia
L & M Education Resource, Delaware
Lawrence Johnson & Associates, Inc., Washington, D. C.
Library for Blind and Physically Handicapped, Honolulu, Hawaii
Mayor's Committee on the Handicapped, Honolulu, Hawaii
Mayor's Office for the Handicapped, New York, N. Y.
Mexican Federation of YMCA, Mexico City, Mexico
National Board of YWCA, New York, N. Y.
National Consortium on Physical Education and Recreation for the Handicapped, Washington, D. C.
National Council of YMCA of Canada, Ottawa, Canada

National 4-H Council, Washington, D.C.
National Recreation and Parks Association - NTRS Section, Arlington, Virginia
National Wheelchair Athletic Association
New York City Mayor's Office
New York City Mayor's Office, Office of Volunteers
New York State Park and Recreation Committee
New York State, Lieutenant Governor, Albany, New York
New York University, New York City
New York University Medical Center - Institute of Rehabilitation Medicine, New York, N. Y.
North American Federation for Temple Youth, New York City
Northeast Region Area Committee on Scuting for the Handicapped (NERACOSH) Boy Scouts of America, Dayton, New Jersey
Office of Disabled, Westchester County, White Plains, New York
Osaka YMCA, Japan
Physically Handicapped and Able Bodied, London, England
Port Authority of New York and New Jersey
President's Committee on Employment of the Handicapped, Washington, D. C.
President's Committee on Mental Retardation, Washington, D. C.
President's Council on Physical Fitness and Sports, Washington, D. C.
Project MAY, Longview, Washington
Recreation Center for the Handicapped, San Francisco, California
Rehabilitation Hospital of the Pacific, Honolulu, Hawaii
Rehabilitation International, New York, N. Y.
Rehabilitation Medicine, Queens Hospital, New York, N. Y.
Rehabilitation Services Administration, Department of Education, Washington, D. C. and New York, N. Y.
Reynolds, Dr. and Mrs. Richard M., Longview, Washington
Sevier, Dr. and Mrs. John A., Springfield, Pennsylvania
Special Recreation, Inc., Iowa City, Iowa
The Sports Council of Great Britain, London, England
Taipei YMCA, Taiwan
Tokyo YMCA, Japan
The United Cerebral Palsy Association, Inc., New York, N. Y.
United States Council - International Year of Disabled Persons, Washington, D. C.
United States Federal Secretariat for the International Year of Disabled Persons, Washington, D. C.
United States Interagency Committee - International Year of Disabled Persons, Washington, D. C.
University of Guan, Agana, Guam
University of Hawaii, Honolulu, Hawaii
University of Iowa, Iowa City, Iowa
University of Maryland, Department of Recreation, College Park, Maryland
University of Missouri, Columbia, Missouri
Waimano Training School and Hospital, Honolulu, Hawaii
Warner Communications, New York, N. Y.
Wassaic Developmental Center, New York, N. Y.
World Alliance of YMCA's, Geneva, Switzerland
YMCA of Honolulu Metropolitan Headquarters, Hawaii
YMCA of Montreal, Canada
YMCA of the USA, Chicago, Illinois
Young Adult Institute, New York, N. Y.

Project Director

Project Mainstreaming Activities for Youth
P. O. Box 1781
Longview, WA 98632
(206) 577-0243

Sponsored by the YMCA of the USA
Special Populations
P. O. Box 1781
Longview, WA 98632

Grace D. Reynolds
Associate Director
Program Development

YMCA of the USA
Special Populations
Box 1781
Longview, Washington 98632
(206) 577-0243

INTRODUCTION

Project Mainstreaming Activities for Youth (Project MAY) was a collaborative in-service training project involving 11 national youth serving agencies and invited resource organizations. The National Board of YMCAs was the funded agency and serves as the Project sponsor.

The major goals of Project MAY were:

- To work with national and regional structures of major youth serving organizations to develop cooperation and share learnings in meeting the needs of handicapped persons.
- To provide in-service training to multi-agency leadership in developing programs for the handicapped.
- To develop materials for use within voluntary youth serving organizations.

The Project also developed techniques and materials to assist organizations in achieving their goals for mainstreamed programs. Assistance was offered both in the area of strengthening the volunteer's role in providing mainstreamed services and in the dissemination of information.

YMCAs for more than twenty years have provided training opportunities in aquatics, camping, club work, and sports events for those with disabilities.

During the past ten years the YMCA of the USA (National Board of YMCAs) has provided leadership for three national cooperative projects:

Project Aquatics (PA)
Project Aquatics Mainstreaming (PAM)
Project Mainstreaming Activities for Youth (MAY)

These special projects received a substantial amount of their funding from the Bureau of Education for the Handicapped and the Office of Special Education Rehabilitative Services.

Through the MAY Project the scope of the collaboration work was substantially expanded to include eleven national youth agencies (American National Red Cross Youth Services Program, Boys' Clubs of America, Boy Scouts of America, Camp Fire, Inc., 4-H Cooperative Extension Services, Future Homemakers of America, Girls Clubs of America, Girl Scouts of the U.S.A., National Jewish Welfare Board, National Board of YMCAs and National Board of YWCA), and over one hundred resource groups. International involvement occurred through the United Nations International Year of Disabled Persons, the World Council of YMCAs and the Project MAY Congresses.

Materials were available to the World Congress, International Council for Health, Physical Education and Recreation meeting in Manila, Philippines, through the efforts of Special Recreation, Inc.

The Office of Special Populations, Program Development Division, YMCA of the USA serves as the office which will continue to promote the thrust of these projects in the integration of persons with disabilities into activities and programs in which they can safely, successfully, and with personal satisfaction participate. The extent of our work will depend on available financial support.

ACKNOWLEDGEMENTS

Project MAY wishes to acknowledge with sincere thanks the cooperation and collaboration of agencies and individuals who have worked together to assist national youth serving agencies in planning, developing, implementing, promoting and evaluating a collaborative program to mainstream youth with disabilities in regular programs.

Special thanks are due to:

The Office of the United States Department of Education,
Office of Special Education and Rehabilitative Services

The MAY Collaborating Agencies:

- American National Red Cross
- Boys' Clubs of America
- Boy Scouts of America
- Camp Fire, Inc.
- 4-H Cooperative Extension Services
- Future Homemakers of America
- Girls Clubs of America
- Girl Scouts of the USA
- Jewish Welfare Board
- National Board of YWCA
- YMCA of the USA

The Resource groups identified on the list of MAY support groups

The Project Officer

The Project staff

The site coordinators for the various Conferences, Congresses, training sessions and other events

The Foundations and individuals who provided financial assistance

United States Council International Year of Disabled Persons

Those with disabilities who demonstrated at the various events

States, counties and municipalities who provided support

Individuals and support groups from outside the United States who attended the Congresses:

National Council of YMCAs of Australia

National Council of YMCAs of Canada

National Council of YMCAs of the Republic of China

National Council of YMCAs of England, Ireland and Wales

National Council of YMCAs of Japan

National Council of YMCAs of Malaysia

Federacion de Asociaciones Cristianas de Jovenes de la Republica Mexicana

Sweden - European Area Committee of YMCAs

United Kingdom

Physically Handicapped and Able Bodied (PHAB)
The Sports Council of Great Britain

United Nations/International Year of Disabled Persons Secretariat

Volunteers - National and International

WE THANK YOU ALL

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The MAV Congress

Sharing Program Trends For The 80's

The New York Hilton Hotel

New York, New York

September 10-12, 1981

Mainstreaming Activities For Youth
(Project MAY)

A collaborative Project to assist national youth serving agencies in planning, developing, implementing, promoting and evaluating a collaborative program to integrate youth with disabilities in programs and facilities of their choice through the process of Mainstreaming

P.O. Box 1781 Longview, Washington 98632
Phone (206) 577 0243

PROJECT DIRECTOR: GRACE D. REYNOLDS
PROJECT OFFICER: WILLIAM A. HILLMAN, JR.

Site Coordinators: Col. William P. McCahill, U.S.M.C. Ret.
Grace D. Reynolds, Program Development Division
YMCA of the USA Project Director

Program Coordinator: John Myers, Executive Director
Eastern Queens Branch YMCA
YMCA of Greater New York

THE MAY CONGRESS
SHARING PROGRAM TRENDS FOR THE 80's

September 10-12, 1981
The New York Hilton Hotel
1335 Avenue of the Americas
New York, New York 10019, U.S.A.

AGENDA
Thursday Sept. 10, 1981

FIRST DAY
September 10, 1981

9:00 - 11:00 a.m. LEADERSHIP MEETING—Regent Parlor, 2nd Floor

10:00 - 12:00 Noon REGISTRATION—Outside of Nassau Suite

11:00 - 12:00 Noon Theatre Presentation by **Intentional Acts**
of the Young Adult Institute, N.Y.C.
Video showing—Nassau Suite

1:00 - 2:45 p.m. OPENING SESSION—Nassau Suite
Presiding: **Solon B. Cousins**
Executive Director, YMCA of the USA

OPENING CEREMONY: **Boy Scouts of America**

INVOCATION: **Harold H. Wilke**
Director, The Healing Community, White Plains, N.Y.
Professor, Union Theological Seminary, N.Y.

WELCOME TO THE CONGRESS

Solon B. Cousins
Executive Director, YMCA of the USA

A project of the National Council of the Young Men's Christian Associations of the United States of America. Corporate Body: National Board of Young Men's Christian Associations. A special project of the United States Department of Education, Office of Special Education and Rehabilitative Services, Office of Special Education

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OFFICIAL WELCOME:

Greetings from **Ronald Reagan,** President, U.S.A.
To be read by Solon B. Cousins

United Nations:

Lyutha Al-Mughairy
Information Officer for the International Year of Disabled Persons, Division for Economic and Social Information, N.Y.C.

New York State:

The Honorable Mario Cuomo
Lieutenant Governor, Albany, N.Y. (Invited)

New York City:

The Honorable Edward I. Koch
Mayor (Invited)

United States Council for the International Year of Disabled Persons:

Harold H. Wilke
Director, The Healing Community, White Plains, N.Y.
Professor, Union Theological Seminary, N.Y.
Board Member IYDP

United States Secretariat for the International Year of Disabled Persons:

Ambassador John W. McDonald
Co-Chairman, U.S. Interagency Committee, International Year of Disabled Persons—1981, Washington, D.C.

Private Sector:

Julie Gilligan
Coordinator of Education Programs
International Paper Company Foundation, N.Y.C.

INTRODUCTION OF REPRESENTATIVES FROM OTHER NATIONS:

2:45 - 3:00 p.m. BREAK

3:00 - 4:00 p.m. **GENERAL SESSION #1—THE STATE OF THE ART—**Nassau Suite

Presiding: **William Howes,** President
Greater New York Metropolitan Board YMCA

INTERNATIONAL OVERVIEW: STATE OF THE ART
Norman Acton, Secretary General
Rehabilitation International, N.Y.

4:00 - 5:00 p.m. **CONCURRENT GROUP DISCUSSIONS BASED ON THE STATE OF THE ART:**

Discussion Group #1 **Recreation/Leisure and Club Activities—**Room #504

Facilitator: **John Nesbitt**
Professor: University of Iowa
President, Special Recreation, Inc.

Resource Persons:

Solon B. Cousins, Executive, YMCA of the USA

Robert R. Dye, Executive, Program Development Division, YMCA of the USA, Chicago, IL.
Mary Essert, Program Coordinator for the Handicapped, Dutchess County YMCA, Poughkeepsie, N.Y.
Gerald Fain, Coordinator of Leisure Studies Dept. Boston University, Boston Mass.
Marcie Goldstein, Asst. Regional Coordinator, N.Y. State Park & Recreation Commission, N.Y.C.
Vivian Harris, Volunteer Coordinator, Boy Scouts of America, N.Y.C.
Fred Humphrey, Chair, Department of Recreation, University of MD, College Park
Richard Morrall, Director of Youth Services, Croydon YMCA, England
Judy Nutter, Youth Representative, Dutchess Co. YMCA Poughkeepsie, N.Y.
Debbie Payerly, Springfield College, Volunteer at Dutchess, Co. YMCA, Poughkeepsie, N.Y.
Janet Pomeroy, Founder & Director, Recreation Center for the Handicapped, San Francisco, Ca.
Dayna Portis, Youth Representative, Future Homemakers of America, Springfield, Ohio
William S. Suzuki, Executive of Camp Branch YMCA Honolulu, HI.
Carla Tabourne, Program Consultant, National Board of YWCAs, N.Y.C.
Terry Thompson, PHAB (Physically Handicapped and Able Bodied), London, England
Libby White, Girls Clubs of America, N.Y.C.
Youth Representatives (See attached roster)
Recorder: **Nelson Leek,** Boy Scouts of America, N.Y.C.

4:00 - 5:00 p.m. Discussion Group #2 **Sports Activities—Room #513**

Facilitator: **Julian U. Stein**
Professor, George Mason University, VA

Resource Persons:

John Christopher, Volunteer, Dutchess County YMCA, Poughkeepsie, N.Y.
Sharon Daly, Volunteer, Dutchess County YMCA, Poughkeepsie, N.Y.
Elizabeth Dendy, The Sports Council of Great Britain London, England
Richard Hoyt Jr., Youth Representative, MA.
Russell Hoyt, Youth Representative, MA.
Benjamin H. Lipton, Consultant, National Wheelchair Athletic Association, Woodside, N.Y.
Wendy Shugol, Volunteer with National 4-H Center, Washington, D.C.
Robert Sweet, Wassaic Developmental Center, Wassaic, N.Y.
Carl Troester, International Council on Health, Physical Education and Recreation, Reston, VA.
Nancy Wall, Youth Representative, Dutchess County YMCA, Poughkeepsie, N.Y.
Youth Representatives (see attached Roster)
Recorder: **William Moors,** The American National Red Cross Volunteer Chairman, Adapted Aquatics, N.Y.C.

4:00 - 5:00 p.m. Discussion Group #3

Rehabilitation Programs—Room #507

Facilitator: **Earl Cunerd,** Executive Director,
United Cerebral Palsy, Inc., N.Y.C.

Resource Persons:

Naomi Bodo, Assistant Director of Rehabilitation
Medicine, Queens Hospital, N.Y.
Susan Claxton, Occupational Therapist Consultant
Conway, Mass.
Richard C. Englehardt, Regional Commissioner, Rehabilitation
Services Administration, Dept. of Education, N.Y.C.
Nahum Lema, Asst. General Secretary, Dar Es Salaam, YMCA
Tanzania
Richard Manley, Director, Office of Disabled,
Westchester County, N.Y.
Louise Priest, Executive Director, Council for National
Cooperation in Aquatics, U.S.A., Manassas, VA.
Jeremiah Teehan, New York City Chairman, IYDP,
Mayor's Office for the Handicapped, N.Y.C.
Youth Representatives (see attached Roster)
Recorder: **Marjorie Murphy,** Director of Aquatics,
YMCA of the USA, Chicago, IL.

4:00 - 5:00 p.m. Discussion Group #4

Vocation and Career Opportunities—Room #529

Facilitator: **Paul Hippolitus,** Employment Advisor,
President's Committee on Employment
of the Handicapped, Washington, D.C.

Resource Persons:

Susan Blocker, Youth Representative, N.Y.
James M. Devaney, Director, Joseph Bulova School
Woodside N.Y.
Denise Figueroa, Mayor's Office for the Handicapped, N.Y.C.
Kathy McGrath, F.H.A. Advisor, South Charleston, Ohio
Larry Passantino, Goodwill Industries, N.Y.C.
E. O. Teye, Ghana YMCA, Accra, Ghana
Dan Winchester, Volunteer Safety Services, The American
National Red Cross, N.Y.C.
Youth Representatives (see attached Roster)
Recorder: **Susan Bowers**
The American National Red Cross, Youth Services,
National Headquarters, Washington, D.C.

4:00 - 5:00 p.m. Discussion Group #5

Education/Family—Room #510

Facilitator: **Judy Hoyt**
Program Director, Association for the
Support of Human Services, Inc., Westfield, MA.

Resource Persons:

Cheryl Anderson, Youth Services Director, The American
National Red Cross, Prince George's County
Chapter, MD
Roxanne Brody, State Advocate for Disabled, N.Y.C.
Thomas Chancey, Youth Representative, N.Y.C.

Shirley Eoff, Adult Education Dept. Campfire, Inc.
Kansas City, MO.
Julie Gilligan, Coordinator of Education Programs,
International Paper Company Foundation, N.Y.C.
Patricia Grant, Parent, N.Y.C.
Barbara Kolucki, Special Education Media Consultant,
USA and Hong Kong
Ruth Laws, President, L & M Education Resource, Dover, DE.
Meredith Milazzo, Youth Repesentative, N.Y.C.
Sandy Pinkerton, New York State Department of
Education, N.Y.C.
John Sevier, NERACOSH, Boy Scouts of America
Springfield, PA.
Douglas Watson, New York University, N.Y.C.
Steve Wells, Boy Scouts of America, N.Y.C.
Youth Representatives (see attached Roster)
Recorder: **Elizabeth Munz**
Girl Scouts of the USA, N.Y.C.

6:30 p.m. **RECEPTION—Petit Trianon**

7:30 p.m. **GENERAL SESSION #II—THE MAY CONGRESS BANQUET**
(Participants and Invited Guests)—Trianon Ballroom

Presiding: **Col. William P. McCahill,** U.S.M.C., (Ret.)
Volunteer, Boy Scouts of America, Arlington, VA.

OPENING CEREMONY: **Girl Scouts of the U.S.A.**

INVOCATION DINNER **Rabbi Daniel Freelander,** Associate Director,
North American Federation for Temple Youth, N.Y.C.

KEYNOTE SPEAKER: **Harold Russell**
Chairperson, The President's Committee
on Employment of the Handicapped, Boston, MA.

SPECIAL RECOGNITIONS

ENTERTAINMENT: **"Kids on the Block"**
New York City Troupe from
The Kid's Project
Marion Dwyer, Kids Project Puppeteer
Elizabeth Ricciardi, Kids Project Puppeteer

SECOND DAY
September 11, 1981

9:00 - 9:45 a.m. **GENERAL SESSION #III—CULTURAL UNIVERSALS IN MAINSTREAMING**
Nassau Suite

Presiding: **Michael J. Lenaghan**
Program Development Director
The American National Red Cross, Washington, D.C.

Speaker: **John A. Nesbitt**
Professor, University of Iowa
President, Special Recreation, Inc.
Iowa City, IA.

9:45 - 10:00 a.m. **BREAK AND CHANGE TO SMALL GROUP DISCUSSION SESSIONS**

10:00 - 11:00 a.m. **CONCURRENT GROUP DISCUSSIONS BASED ON CULTURAL UNIVERSALS IN MAINSTREAMING**-On 5th Floor

*See General Session #1—Concurrent Group Discussions
for names of Resource Persons and their affiliations

Discussion Group #1
Recreation/Leisure Programs—Room #504
Facilitator: **John Nesbitt**
Resource Persons: *
Recorder: **Mary Essert**

Discussion Group #2.
Sports Activities—Room #513
Facilitator: **Julian U. Stein**
Resource Persons: *
Recorder: **William Moors**

Discussion Group #3.
Rehabilitation Programs—Room #507
Facilitator: **Earl Cunerd**
Resource Persons: *
Recorder: **Louise Priest**

Discussion Group #4.
Vocational Opportunities—Room #551
Facilitator: **Paul Hippolitus**
Resource Persons: *
Recorder: **Susan Bowers**

Discussion Group #5.
Education/Family—Room #510
Facilitator: **Jack Dinger**
Professor of Special Education, Slippery Rock, PA.
Boy Scouts of America—Chair, NACOSH Committee
Resource Persons: *
Recorder: **Elizabeth Munz**

11:15 - 11:45 a.m. **REASSEMBLE FOR REPORTS FROM CONCURRENT GROUPS**—Nassau Suite

Presiding:
Roxanne Spillett
Program Director for Health
Boys Clubs of America, N.Y.C.

12:00 - 1:45 p.m. **GENERAL SESSION #IV—COORDINATING RESOURCES**—Regent Room

Presiding:
Grace D. Reynolds
Staff Associate for Program Development for Special Populations
Program Development Division
YMCA of the USA, Longview, WA
Project MAY Director

INVOCATION:
William S. Suzuki
Director, Camp Erdman Branch
YMCA of Metropolitan Honolulu, Hawaii

LUNCHEON:

KEYNOTE SPEAKER:
Janet Pomeroy
Founder and Director
Recreation Center for the Handicapped
San Francisco, California

RESPONSE TO KEYNOTE SPEAKER:

Harold H. Wilke
Director, The Healing Community,
White Plains, N.Y.
Professor, Union Theological Seminary,
New York, New York

2:00 - 3:00 p.m. **CONCURRENT GROUP DISCUSSIONS BASED ON COORDINATING YOUR RESOURCES**

*See General Session #1—Concurrent Group Discussions for names of Resource Persons and their affiliations.

Discussion Group #1.
Recreation/Leisure Programs—Room #504
Facilitator: **John Nesbitt**
Resource Persons: *
Recorder: **Mary Essert**

Discussion Group #2.
Sports Activities—Room #513
Facilitator: **Julian U. Stein**
Resource Persons: *
Recorder: **William Moors**

Discussion Group #3.
Rehabilitation Programs—Room #507
Facilitator: **Earl Cunerd**
Resource Persons: *
Recorder: **Marjorie Murphy**

Discussion Group #4.
Vocational Opportunities—Room #551
Facilitator: **Paul Hippolitus**
Resource Persons: *
Recorder: **Susan Bowers**

Discussion Group #5.
Education/Family—Room #510
Facilitator: **Jack Dinger**
Resource Persons: *
Recorder: **Nancy Garfield**

3:00 - 3:15 p.m. BREAK

3:15 - 3:45 p.m. **REASSEMBLE FOR REPORTS FROM CONCURRENT GROUPS**—Nassau Suite

Presiding: **Roxanne Spillett,** Program Director for Health,
Boys Clubs of America, N.Y.C.

3:45 - 5:15 p.m. **GENERAL SESSION #V—OVERVIEW OF CONCURRENT WORKSHOP SESSIONS**

Overview: **Frances Hesselbein**
Executive Director, Girl Scouts of the USA, N.Y.C.

4:05 - 5:15 p.m. MOVE—RECONVENE FOR CONCURRENT WORKSHOP SESSIONS

SESSION I — Nassau Suite

Session Focus: Activity Demonstration with Youth Participants

Introduction By **Vivian Harris**
Chairperson, Scouting for the Handicapped
Committee, Boy Scouts of America, N.Y.C.

Presenter: **Dr. Julian U. Stein**
Professor, George Mason University, VA

SESSION II -- Room #504

Session Focus: A Special Family: Integrating Severely Handicapped
in Recreation, Leisure and School Activities

Introduction By: **Robert R. Dye**
Director, Program Development Division
YMCA of the USA, Chicago, IL

Presenters: **Judy Hoyt,** Program Director,
Association for Support of
Human Services, Inc., Westfield, MA
Richard Hoyt, Jr., Westfield, MA
Russell Hoyt, Westfield, MA

SESSION III -- Room #513

Session Focus: Everything you wanted to know about
section 504 of the Rehabilitation Act,
and how it might affect your programs
and facilities

Introduction By: **Susan L. Niman,** Project Assistant, Project MAY,
Longview, Wa.

Presenters: **David Goldenberger**
Consultant, Lawrence Johnson & Associates, Inc.,
Washington, D.C.

4:05 - 5:15 p.m. **SESSION IV—Room #507**

Session Focus: Effective Linkage in the Community:
Mainstreaming High School and College
Students with Disabilities Into Primary Labor
Market: The Process and the Goal

Introduction By: **Mary Essert**
Program Coordinator for the Handicapped
Dutchess County N.Y. YMCA

Presenters: **Marilyn Sommers,** Assistant Coordinator,
Career Placement Work Experience for Disabled Students
(WEDS) Program, Institute of Rehabilitation Medicine,
New York University Medical Center, N.Y.C.

Barbara Wolff, Placement Specialist,
WEDS, New York University Medical Center

Robert Gardner
Student and Participant in WEDS

Bobbi Linn
Director, Consumer Affairs,
Center for Independence of the Disabled in NY

Holly Blauser,
Personnel Representative for Port Authority
of New York and New Jersey.

Other representatives from
linkages in the community

5:15 - 6:30 p.m. **SOCIAL HOUR**—Regent Room

8:00 - 10:00 p.m. **FILM THEATRE**—Green Room
Coordinator: **Susan L. Nisnan**
Film Selection: **Julian U. Stein**

THIRD DAY
September 12, 1981

9:00 - 11:30 a.m. **GENERAL SESSION #VI—MEDIA PRESENTATION**—Nassau Suite

Facilitator: **Carla Tabourne**
Program Consultant, National Board,
YWCA of the USA, N.Y.C.

Film: "Out of the Shadows"
Recreation Center for the Handicapped
San Francisco, CA.

9:30 - 9:45 a.m. **INTRODUCTION OF POSITION PAPER:**

Nancy Garfield, Director of Special and
Innovative Projects, Program
Department, Girl Scouts of the USA, N.Y.C.

Saturday, Sept. 12, 1981

9:45 - 11:00 a.m. **GENERAL SESSION #VII—STRATEGIES FOR THE FUTURE INTERNATIONAL UPDATE**

Introduction: **Carla Tabourne,** HPER Consultant
National Board of YWCA of the USA

Moderator: **Elizabeth Dendy,** The Sports Council
London, England

The United Kingdom: **Terry Thompson,** Director of PHAB (Physically
Handicapped and Able Bodied), London, England

Richard Morrall, Director of Youth Services,
Croydon YMCA, England

Europe: To be announced

Africa: **Nahum Lema,** Tanzania, Representative of
African Alliance YMCA

E. O. Teye, Chairperson, Ghana YMCA Board
of Directors, Accra, Ghana

Canada: **Richard A. Patten;** Director of the Ottawa Office,
National Council of YMCAS
of Canada, Ottawa, Canada

U.S.A. **Robert R. Dye,** Executive, Program Development
Division, YMCA of the USA

Mexico: To be announced

11:00 - 11:30 a.m. **GENERAL SESSION VIII—FOCUS ON THE FUTURE**—Nassau Suite

(Coffee Available in the Room)

GENERAL DISCUSSION OF THE POSITION STATEMENT BY THOSE ATTENDING CONGRESS:

Facilitator: **Nancy Garfield**
Girl Scouts of the USA, N.Y.C.

12:00 p.m. **GENERAL SESSION IX—EXTENDING BENEFITS OF THE INTERNATIONAL YEAR OF DISABLED PERSONS**—Regent Room

Presiding: **John Myers,** Executive Director
Eastern Queens Branch YMCA, N.Y.C.

INVOCATION: Member of the Catholic Diocese of New York

Speaker: **Harold H. Wilke**

1:45 p.m. **FINAL PRESENTATION OF REVISED POSITION STATEMENT**

Presiding: **Nancy Garfield**

2:00 p.m. **WRAP-UP: John Myers**

Acknowledgements

Our special thanks for assistance with additional funding:

International Paper Company Foundation gift which has made the MAY plaques of appreciation possible and for leadership in establishing a scholarship fund for youth participation.

The President's Committee on Employment of the Handicapped

ARCO

Dr. and Mrs. John Sevier

Exxon Corporation
Warner Communications

Names of other corporations were not available at the time of the printing of this agenda.

Photographers:

William Arango, Director of Special Projects, YMCA of Greater New York

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Susan L. Niman, Project MAY

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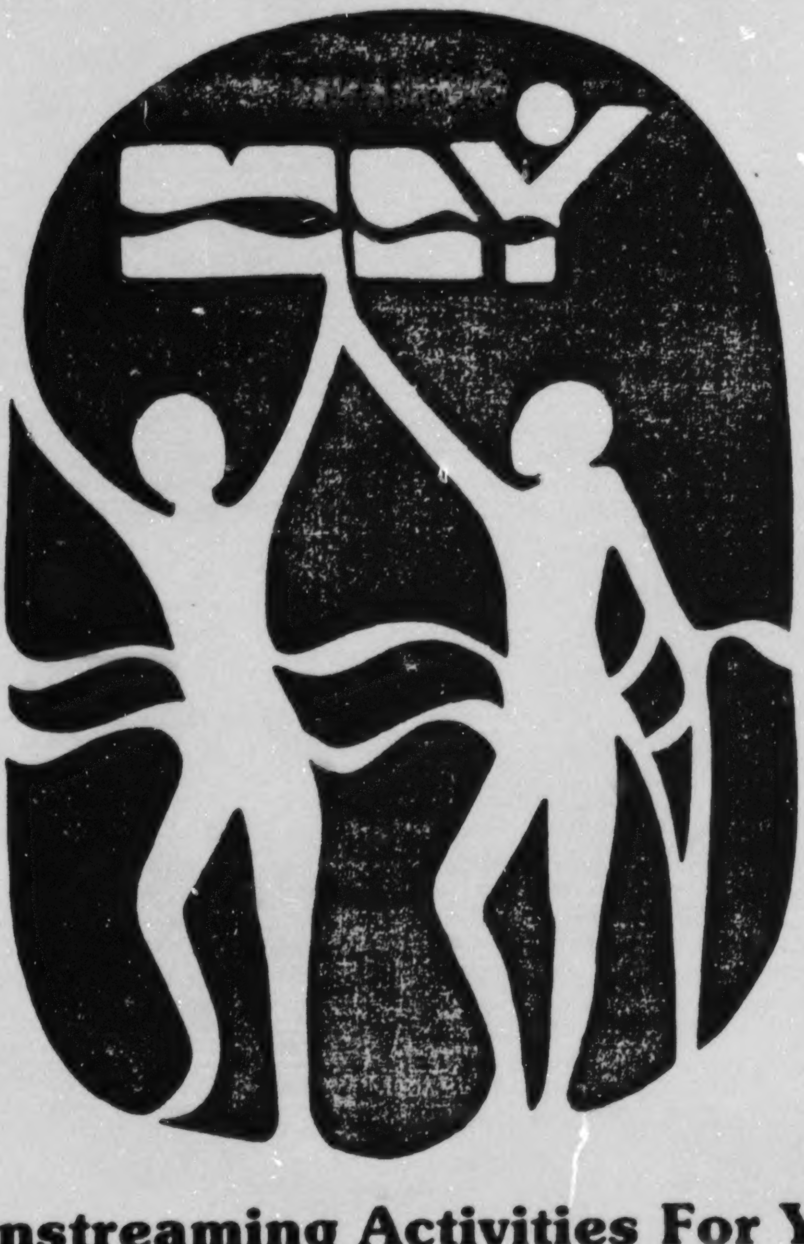
Janet Thompson, Project Assistant
Esther Hewey, Project Volunteer

YES WE M.A.Y.



Mainstreaming Activities For Youth

WELCOME TO THE CONGRESS

by

Solon Cousins
Executive Director, YMCA of the USA

What a great occasion it is to be here in this place for these days. I would like to take a personal moment to welcome you on behalf of all the YMCAs all over the United States and, in fact, around the world. We are very proud, as an organization, to be the coordinating agency for Project MAY. Among many others who applaud your participation and your attendance is our Program Director of Program Development for Special Populations, Grace D. Reynolds of Longview, Washington. Others who applaud are people from the U.S. Department of Education, Office of Special Education and Rehabilitative Services. Also our New York hosts and coordinators: Col. William P. McCahill, USMC Retired; and John Myers, Executive Director of the Eastern Queens Branch of the Greater New York YMCA.

I would like now to read a special message addressed to all of us. It is as follows:

International Year of Disabled Persons - 1981

> "We seek in the 1980's an era of national renewal, an era that will set loose again the energy and ingenuity of the American People. Today there are 35 million disabled Americans who represent one of our most under-utilized resources. Their will, their spirit and their hearts are not impaired despite their limitations. All of us stand to gain when those who are disabled share in America's opportunities.
>
> To increase the participation of disabled persons in our national life and in the lives of other nations, the United Nations has designated 1981 the International Year of Disabled Persons. America has long been a world leader in this area and the United States Council for the International Year of Disabled Persons and our federal government have already responded to the United Nations challenge. Programs are under way throughout the nation. Through partnerships of disabled and non-disabled persons of our private sector and our government, and of our national, state and community organizations, we can expand the opportunities for disabled Americans to make a fuller contribution to our national life.
>
> I am proud to pledge the cooperation of my administration and the federal agencies under my jurisdiction, including the Federal Interagency committee for the International Year of Disabled Persons."

From the White House

(Signed) RONALD REAGAN
President, United States of America

Welcome to the Congress

As we begin these three days together, let us remind ourselves of the basic mission that brought us here in the first place. The mission of Project MAY. You will recall, it is to assist youth serving agencies in planning, developing, implementing, promoting and evaluating a collaborative program to mainstream handicapped youth in regular programs.

What a unique project; bringing together eleven national organizations and over twenty other national resource groups. We are all committed to developing materials, sharing our program resources, studying trends, examining our successes and our failures. We all need enough failure to keep us humble and enough victories to keep us going. We have had some of the former, a lot of the latter. MAY Project agencies, the eleven, all together have a membership in the United States of over 50 million citizens. What an environment in which to develop our program in awareness of people throughout our nation and society around the world.

Fifty million is also the number of people in the United States who are living with disabilities of one kind or another according to the 1980 census. We know that we simply must make our facilities and programs accessible and available to people with disabilities. Call it mainstreaming, call it integration, call it assimilation, or call it just plain common sense, we are thinking and going in our own best interests as citizens and as agency leaders. This International Year of Disabled Persons - 1981 gives us a focus opportunity to raise our own awareness, our own commitment and that of the local national and international community. We must attract the leadership of our organizations so that we can move great and creative ideas into the implementation that will pay off for all of us, youth and adults.

These days we will be concentrating on our agency programs for all youth; recreation/leisure, sports, rehabilitation, vocational training and family education. It is a special pleasure to have young people among us. We will be enriched by their presence and by the contributions they will make to our meetings and to the overall goals of the Congress. We need growth, we need improvement. We need to take what we have and move forward. We have, in this room; the wherewithal, the brainpower, the commitment to move us into another time, another future that will find our goals attainable in my judgement.

We have a distinguished group of speakers at this Congress and we have program discussion for all to suit your interests. As you know, this is one of two multi-regional congress sessions, the other to be held at the end of this month in Hawaii.

I wish you every success in this Congress and, again, our YMCA organization is proud to be identified with, supportive of, and stimulated by what you are doing.

UNITED NATIONS

by

Lyutha Al-Mughairy
Information Officer for IYDP - U.N.

I would like to thank you for the honor of inviting me here and it gives me great pleasure to have this opportunity of participating in the activities of Project MAY. Moreover, I would like to thank you for creating this opportunity to have all of us gain additional inspiration and focus on issues and projects of our mutual interest.

Ladies and Gentlemen: On behalf of Mrs. Leticia Shahani, United Nations Secretary-General's Special Representative for the International Year of Disabled Persons, I should also like to thank all of you for the honor of inviting her to address the Multi-Regional Conference of your organization in commemoration of the International Year of Disabled Persons. Unfortunately, she could not be here with us today because of other commitments. However, she extends her warmest greetings and congratulates your organization on the excellent work it has been doing to promote the objectives of the IYDP in the United States.

The United Nations appreciates the initiative of your organization in organizing this conference which truly expresses the theme of the year - full participation and equality. It is important to record this proclaimed by the United Nations General Assembly in order to reaffirm the determination of the International Community to work for the cause of disabled persons. Not just out of sympathy and compassion, but in full recognition of their capabilities and rightful place as full and equal members of their community. The significance of this commitment is even more apparent when we pause to consider that as many as 500 million human beings in the world are estimated to be physically disabled or mentally retarded.

We bear a collective responsibility to give the disabled every possible assistance to lead useful and productive lives. It is impossible to completely eliminate disability, however, there is a great deal that societies can do to give the disabled their rightful place in the community. We can give them access, not only to buses and buildings, but to life itself. Jobs, support, creative pursuits, and above all, to our minds and hearts. We can assure that they are given the legal protection and practical facilities that will enable them to develop their capabilities and become self-reliant. We can tear down not only the physical barriers that impede their mobility, but the mental attitude that keeps them from those whose world they share. Awareness, advocacy, action can help create a society in which full participation and equality is more than a slogan, but an accepted way of life.

The United Nations has sought within the past decade to deal with the problems of disabled persons. To ensure their rights and facilitate their integration into society have been the central aims of the United Nations policies and programs on behalf of disabled persons. The overall purpose of these policies is to enable the physically and mentally handicapped to contribute effectively and to derive appropriate benefits for their efforts. The International Year of Disabled Persons is a combination of all these efforts and at the same time, the beginning of a continuing and cooperative endeavor for a plight of human cause. This celebration in which we are participating today highlights not only the ideas and aspirations of the participants, but must also strengthen our common determination to make this world of ours a more prosperous and equitable place for all of us.

STATE OF NEW YORK

by

Mary Ann Bollinger
Represented The Honorable Mario Cuomo

I welcome you to New York and to this Conference. The Lieutenant Governor chairs the New York State Commission on the International Year of Disabled Persons and has been very involved, for quite a number of years, in working in this effort. I am glad to be here to thank you for being here and to express our appreciation for the fact of this conference and our full support of its objectives. We are all involved together in this mission to promote opportunity for our largest minority to participate in all aspects of American society; work, play, health care, worship, family life, and the ballot box.

We must all be involved together in this effort to switch the focus from limitations and inabilities to strengths and abilities. In other words, as was said before, to develop more positive attitudes.

New York, like the states you represent, has made much progress in recent years to enable the disabled to be a natural part of the mainstream. We were the first state to establish a State Office of the Advocate for the Disabled, now ably filled by Dr. Francis Berko. New York is second only to the Federal Government as an employer of the disabled and major strides have been made in housing, recreation, education, employment, training, and in numerous other ways including right now, a major effort on prevention. We still have a long way to go as do each of your states, but our commitment is real, as is yours.

However, we all know that government can't be all of this in a vacuum. Community groups, such as yours; churches, voluntary agencies, have been and must continue to work in partnership and especially with challenges from the economy and a degree of self-centeredness that seems to be pervasive in today's society when we must heighten our joint efforts in imaginative ways.

As a parent of two disabled youth and, as a person with a hidden handicap, I look forward to being with you for a part of this conference and to working with you toward implementation of your goals, those goals that we all have in common.

UNITED STATES COUNCIL
FOR THE
INTERNATIONAL YEAR OF DISABLED PERSONS

by

Harold H. Wilke
Director, The Healing Community

I need to share with you some of the frustrations which we have within the religious community. There are some very good things which have been happening in religion and there are, at the same time, some unfortunate ones that are millennial old and in that sense, of course, they represent the whole of our society.

One of these that we are working on within the religious community is the kind of old-wives tale, old-husbands talk; that goes across the country and indeed around the world that says that sin and disability are together. That one is the cause of the other and, whether we look at this from the point of view of John's statement of the account of Jesus' statement, in the Gospel according to St. John, or if we look at it from other's religious accounts, this is not the case, at the very basis of religious feeling.

One of our concerns in this International Year, is to lay to rest this idea that sin and disability are together. Quite obviously there are times when we recognize that certainly sin has had something to do with disability. When my friend is injured in a drunken driving accident, we recognize something of what is involved there in the relationship of sin and disability. Even that, of course, has many qualifications and we need to see it in that way. We need to recognize that the religious community has a tremendous amount to give even as it also has a good deal to overcome within its own environs, within its own boundaries. We want you to help in that. We want you to carry this message of the way in which all of us can work together into your own religious communities, whichever they be, for we see this mainstreaming concern of ours in recreation and working together and praying together, in so many ways, and we recognize that religion is indeed an important part of it.

I want to share with you just one very brief part about play, as it is seen, not alone in simply the fun that we have in playing together, but in the way in which it provides for us new understanding of the human values of the ethical system by which we work. That one has to do with a time that my father taught me to swim. I had a talk with my father a few nights ago. My father died some fifteen years ago, but as with most of us, we continue to talk with our parents. That parent in the ego of each one of us is, of course, still there and it does us good to talk on occasion; to converse on occasion, with parents long gone as well as others, long gone or with us.

I said in a conversation with Dad that went something like this, "Dad, I am grateful to you that you taught me how to swim. You knew that my two brothers and the neighbor kids were out there every day in the creek in the summertime and that somehow I had to do more than paddle around the edges. Dad, I remember how you fixed up that one plank three feet long. You secured at each end an empty one-gallon syrup bucket to keep that plank afloat and then you told me to put my chest right there on that plank and push out into the water. Dad, you went to a lot of trouble to do that and you watched me go out, swim across the pool and then come back again.

Finally you said, 'Now you can do it without the plank,' and I pushed out into the water, went down, came up sputtering, went out again, came up sputtering, and the third time swam dogpaddling fashion all the way across the creek. Dad, I have enjoyed swimming ever since. It has been a great boon for me. Far more than fun, however, was my realization of what is your expectation. You expected that I could do this and you fixed it up so that I could learn and that expectation, that sense of learning was part of a religious heritage which was ours. You shared that with me and I am grateful to you for it."

OFFICIAL WELCOME FROM UNITED STATES SECRETARIAT FOR THE INTERNATIONAL YEAR OF DISABLED PERSONS

By

John C. McDonald
Co-Chairman, U.S. Interagency Committee, IYDP

Good afternoon. It is a pleasure to be with you this afternoon. I thought I would begin by building a bit on what Miss Al-Mughairy talked about concerning the United Nations, try to explain how the U. N. got involved in this whole thing; talk about U. S. Government participation; some of the things, some of the successes we have had, some of the aspirations; and then go on into the future a bit and talk about youth per se in the next four or five years and see if somehow I can plant a few ideas which you can take back to your groups in the next few days to see if you can build on those ideas and develop an interaction for Project MAY in the future.

You have in your kit the 1948 Universal Declaration of Human Rights. I think it is a very appropriate document to start with because it stresses the need for improved social progress and really we are talking fundamentally about that particular concept. It was in 1971 that the General Assembly of the United Nations became specifically involved in the concerns of the handicapped. They adopted, in that year, a Declaration on the Rights of the Mentally Retarded Person. This Declaration points out that the mentally retarded have the same rights as other human beings. I think this sounds very normal for us today, but when you consider that over 150 nations in the world agreed to that text, it begins to have a different import. The Declaration states that they have a right to medical care, economic security, a decent standard of living and most important of all, a right to participate in community life. This Declaration was adopted unanimously by all member states. In 1975, some four years later, the UN adopted a Declaration on the Rights of Disabled Persons and this Declaration pointed out that they have the inherent right to respect for their own human dignity. They have the same rights as their fellow citizens to enjoy a decent life as normal and as full as possible. A very interesting additional provision was added after the debate, saying that the disabled have the right to live with their families and to participate in all social, creative or recreational activities. Another very important landmark, as we build toward this concept of IYDP, was passed unanimously by all member states.

In 1976 it was the Libyan government, that is the government, if you remember, on the north coast of Africa. That government, the Libyan government, proposed to the General Assembly of the United Nations in 1976 that 1981 be declared International Year of Disabled Persons. Many persons ask me, "Why Libya? Why did they get involved in this kind of a concern?" If you go back in history a bit, many of you will remember that during WW II the armies of the west, Germany on one side and the western nations on the other, moved back and forth across the sands of the Sahara a number of times. There were great tank battles fought there on Libyan territory and each time an army moved across that desert, they sowed thousands and thousands of land mines in that area and the other army moving back would do the same thing. So what happened after WWII was over was that tens of thousands of these land mines still were in the desert sand and many, many people have become disabled and crippled in Libya because of accidentally exploded land mines left there from WW II. So they have a much higher percentage of their population who are disabled than any other country, and it was this interesting coincidence of ideas that stimulated them to action. The General Assembly agreed, of course, as you know, and this year was declared to be IYDP with full participation and equality as the theme and the symbol for the year.

On the UN side itself as an effort to stimulate greater action, first of all the secretariat was established in Vienna, Austria for the IYDP. Then a 23 nation advisory committee was set up, of which the U. S. government was a member. Frank Bowe, who is known to some of you here, was our first representative at that meeting in 1979. They developed a plan of action for 1981 which urged that every member state in the United Nations first of all issue a proclamation the beginning of the year urging the concept of full participation and quality. Secondly, they were to establish some kind of a national mechanism, a national committee to focus attention at the local and national level on the concerns of the disabled and that they prepare an activity program for the year. Then at the end of the year they were to prepare a national report which would go to the United Nations and would eventually be brought together in a global report sometime in 1982. They also urged that each government and each country involved develop some kind of a mechanism for 1982 and beyond. In other words, it was very critical that we do not build up to 1981 and then on December 31 forget about the problems of the disabled because the year is over. It was a critical part of the plan of action from the very beginning that we think beyond the year itself. I think it is fair to say that the United States government and the U. S. Council and the private sector side have worked very closely and very well together to insure that these goals, insofar as the United States is concerned, have been met and are being met. This advisory committee met for a second time last year to look at a draft document which the secretariat in Vienna put together about 1982 and beyond. Unfortunately, the document did not meet standards that many felt important, and after considerable debate, the report was sent back to the drawing board and the Secretariat was urged to recast it and come up with a stronger text.

The third meeting of the advisory committee took place last month in Vienna. Our delegation was led by Hal O'Flaherty, blind, who is the Executive Director of our Secretariat in Washington. Interestingly enough, he was the only disabled person to lead a delegation for that particular conference. The delegates worked very hard and finally adopted in a draft form, a document of some 160 paragraphs, which defines three key areas: prevention, rehabilitation and equalization of opportunity as the basic theme for this plan for 1982 and beyond. A number of specific recommendations were made in this text for the national and the regional and at the international level and they urged action,not only by governments but by private organizations, such as those gathered here today. This text will be adopted by the General Assembly and then will move into court. I might add that I brought a copy of that text with me and I will be happy to turn it over to your own leaders here for whatever use they might put it to. But I think it is fair to say that it is a very solid document.

On the U. S. Government side, you have already heard the proclamation which President Reagan issued. We were together in the oval office at that very inspiring ceremony and I must say that I felt the new administration was off to a good start in this particular area. In our interagency planning started two years ago, we set up certain goals. We felt, first of all, that every government agency in Washington should be personally involved in this whole concept. They should be involved not only with their own bureaucracy, their own structures, but they should be concerned about the impact they have on their programs across the whole United States. We now have some 42 different government agencies. Perhaps you didn't realize there were that many, but just about every agency that is in Washington is now involved both with an in-house program expressing concern for the disabled and also involving themselves at the administrative level. The second goal of our committee is to raise the awareness level throughout all of the state, federal and local structures - the goals of the IYDP. The third was to inform citizens of our country about those goals, and the fourth was to interact at the international level to try to learn from other countries what they are doing and to try to explain to them and share with them the kinds of things that we are doing. You have heard about the U. S. Council which is a very fine and a very strong private sector group that is located in Washington and with whom we work very closely. We have continued support from the White House with President Reagan having appointed Miss Virginia Knauer as his representative for the IYDP. The Congress of the United States has passed joint resolutions setting forth the goals for the year and urging that these be followed. We, on our part, have taken some two feet of national reports from the various agencies involved and have boiled them down to a fifteen or eighteen page document which highlights the actions that the United States Government is taking. In the media field we are now proud to report that over 200 press clippings a day are coming into Washington from across the country talking about the problems of the disabled, IYDP and what local action is taking place to resolve some of these issues.

We have had some interesting things happen on a wider basis. Early this year we helped two different communities, Niagara Falls, New York, and Niagara Falls, Ontario, set up what they call an Operation Horseshoe which was to involved 15,000 people from Canada and the United States in a very dramatic two day meeting in honor of the disabled. The highlight of that meeting was the gathering of a three-mile long human chain from the Canadian side of the border, across the International Bridge and down the United States side, with a flare going up and 12,000 candles being lighted simultaneously in honor of the IYDP. The interesting thing about this was that in this interaction between these two highly competitive cities, competitive from a tourist point of view, they have now learned for the first time in their history to work together. It was IYDP that brought them together. This was such a successful program that we have decided, with the cooperation of El Paso, Texas and Juarez, Mexico, to have the same concept - Hands Across the Border - between Mexico and the United States, to take place later this month in El Paso and Juarez.

Another interesting event is taking place next month. Some 350 disabled Japanese veterans are paying their own way to the United States to lay a wreath at the tomb of the Unknown Soldier in Arlington and then attend a reception for them at the State Department. Again, an interesting interaction between the disabled people and the non-disabled.

Chincoteague, Virginia, which is a part of a national park, and the Department of the Interior proudly told us and showed us how they could make a national park accessible to the disabled, including going over the sand dunes in wheelchairs and down into the water in the Atlantic Ocean itself. So I think it is fair to say that a great deal is happening that we can be proud of. Again, on a global basis, about 125 countries now have set up national conventions. They are holding the kinds of meetings that are taking place here today. They have made speeches and issued proclamations. Twenty-five nations have issued special stamps in honor of IYDP, including the United States. For the future, each nation, as I indicated a moment ago, will provide a national report which will be combined into a global document. This can also be a very boring document, of which we have had many. I have been forced to read them. I have an idea that I hope will alleviate that situation of boredom. What I want to do is have the UN, through a private publishing company, pull together the ideas that have been generated and found in these national reports, or ideas that you all have, and put them down in a paperback book which can be sold inexpensively around the world to pass these ideas on to local communities world-wide. Much has been generated to date in this year and I just feel that it should not be lost and that these suggestions and proposals can strengthen this concept beyond 1981. I am urging that this be done.

On our own part, institutionally speaking, we have contacted Dr. Rusk, chairman of the National Council on the Handicapped, among some of his other functions. This is a council which has been established by congressional decree to be the official mechanism, the official body within the U. S. Government structure to overview and look after IYDP in 1982 and beyond. We are in pretty good shape at the moment and we, of course, need help from all of you to insure that this enthusiasm and knowledge and great understanding is viewed as a continuum. In other words, this means that we do continue and that we not come to a screeching halt by the end of the year.

I was asked to talk about something which I feel does relate to your basic concern. Now you all know about IYDP-1981. What you don't know is that in 1985 the United Nations has already agreed to something called International Youth Year, which we call IYY. This is what I think can be of critical importance to you. Very briefly, the United Nations began talking about the problems of youth in 1965. In 1970 there was a World Conference on Youth in New York City which was a disaster. I was involved in the selection process. The ground rules were that each country should have five delegates to the conference. The United States group, such as your own, put in, I think, a total of 300 requests for individuals to be on that five person delegation. You can imagine there was blood on the floor before the final selection process was completed. Because the United States takes things literally, the youth were young. Not many governments take things that literally. The average age of the U. S. delegation was 19. Unfortunately, the average age of the Soviet delegation was 43. You can see that there were certain differences, shall we say in experience and certainly difference in perspective. In any event that conference cooled enthusiasm for some years about holding a second World Conference because not a great deal of practical impact was generated by it. It wasn't until 1977 that the General Assembly, seven years later, began talking about not another conference, but a special year which was focused on the concern about youth, particularly at the local and national level. This idea picked up support, and in 1979 the General Assembly declared 1985 as IYY. Last December a 24-nation Advisory Committee, again the same mechanism as IYDP, was established and the first meeting I attended took place last April in Vienna. The theme of IYY is "participation, development and peace". This calls attention, obviously, to the need for full participation by youth. It focuses on the youth critical role in the whole economic development process and stresses the fact that peace and development go hand in hand. But like all things in the United Nations, there is more to it behind those words than you would hear on the surface. Very simply, the Western world, the developed world, the part of the world that we are from, pushed the concept of participation for youth. The poor countries of the world, the developing world, pushed the concept of development for youth. Eastern Europeans pushed the concept of peace. So there you have it in a nutshell, really the differences of perspective between these three different parts of the world. But the General Assembly felt it was imperative to "harness the energies, enthusiasm and creative abilities of youth to the paths of nation building", a very highflown statement. They went on to say that preparation and observation of IYY would offer a significant opportunity for drawing attention to the situation, needs and aspirations of youth for increasing cooperation at all levels in dealing with youth, and for involving young people in the study and resolution of major international, regional and national problems.

One of the first things that I found in involving myself internationally or globally in this area was that no one had a definition of youth. I don't know whether you have struggled with this in your own organization. It turns out, on a national basis, that every country in the world has a slightly different definition. In some countries youth goes down to the age of ten and in some countries you stop being a youth at the age of 40. The United Nations, for statistical reasons and that is certainly a very important reason, has declared that 15-24 are the ages for youth. I think that is important to bear in mind even though national definitions may vary, because this is going to be the thrust of the year itself. Again on differences, one should remember that the Eastern Europeans, if one can put this group of nine countries together in a group, look upon youth more as a political instrument to extend political action groups then with youth and bring them together and they actually hold world conferences or regional conferences with this political aim in mind. I think it is fair to say that the West, on the other hand, looks at youth from a service oriented perspective. This is certainly what you are involved in yourselves as far as youth is concerned. The third world looks again differently. As I said earlier they look upon youth, I believe, as a resource for development. The preparatory committee had its meeting, agreed to a plan of action for what should happen between now and the end of 1985. This will be on the agenda for the General Assembly in November of this year and will be, I believe, adopted by all member states. We, in our part in Washington, have organized an interagency committee of the federal government bringing all interested concerns together. I think more importantly, at least more importantly to youth, is that I also have organized a non-governmental group and brought them together, which consisted of some 25 people at this first meeting which took place the end of April. We had the YMCA, the Boy Scouts, PTA, Catholic Youth, Boys' Clubs of America, 4-H Council, American Red Cross and a half a dozen more institutions represented at this first gathering. The purpose of this meeting was: a. to have a debriefing on what happened at the April meeting, and b. to begin to think ahead for 1985.

I think it is very clear that we all recognize that a youth year, in particular a youth year, cannot be successful in the United States without the major involvement of the organizations which you represent here today. And so, in looking at the future, and by the way there are a series of events tomorrow, if some of you could steal away to the United Nations, about International Youth Year. I just wanted to mention that in passing. I think that what I would like to see you all do in the course of the next few days, when you are talking about the future for Project MAY, is to keep in mind a particular sentence in this plan of action for International Youth Year, which was just adopted a matter of weeks ago. That sentence says in the proposals put forward by this document: "The emphasis should be put on activities and respect of the most disadvantaged youth groups in society in accordance with the specific conditions of every country".

It is clear to me, based on my experience with the disabled, that disabled youth are a disadvantaged youth group. I would hope that in your planning sessions you would seriously consider a possibility of combining your interest in IYDP with the concern of International Youth Year and youth itself. Since the purpose of IYY is to stimulate concern at the local and at the national level, it seems to me that your efforts on behalf of disabled youth would combine these very fundamental issues which you are concerned about, both for the betterment of youth and for the betterment of the disabled of America. Thank you very much.

PRIVATE SECTOR

by

Julie Gilligan
Coordinator of Education Programs
International Paper Company Foundation

I think by now you must be all welcomed out. It is a real pleasure to bring greetings and a lot of praise from the business sector to all of you.

Project MAY has certainly demonstrated sensitive and very effective leadership in mainstreaming. As I traveled around this past year to International Paper Mill communities, I have heard from our local managers about their high regard for youth agencies. They have indicated that there has been a marked increase in the quality of family life in any of the towns where there are groups sponsored by youth agencies such as are in this room; whether they be 4-H, the Girl Scouts, the Y.

It is the hope of this foundation that you will continue to mainstream disabled young people in your various kinds of programs. Further, it is our hope that many more of these youth programs will be mainstreamed into rural communities where you are needed very much.

On behalf of International Paper and the other corporations who responded so quickly and so generously to the youth scholarship fund, I wish you a very happy and productive Congress.

INTERNATIONAL OVERVIEW: STATE OF THE ART

By

Norman Acton

Secretary General, Rehabilitation International

When I sat down the other day to think about what I should be saying to you today, I looked at the title I had been given which was to talk about the State of the Art. I was somewhat embarrassed to realize that I didn't really know what that meant in this context. As I thought about it I remembered Picasso's statement once after he had painted a portrait of Gertrude Stein and someone said, "That doesn't look very much like Gertrude Stein". Picasso said, "Never mind, eventually Gertrude Stein will look like the portrait." Or there was the problem that Rodin, the sculptor, had when he was doing a sculpture of Victor Hugo and he did it in heroic proportions with Victor Hugo standing on a rock with all kinds of muses and kings and one thing and another milling around underneath him and the waves beating on the rock and everything. When he had finished the plaster cast for this and it was so large it had to be in a kind of extemporaneous studio, he called the press in to see it. Just before the unveiling there was a great storm and unfortunately, it had washed away quite a good deal of all of his work. The kings and the queens and the muses were reduced to slime and rubble and Victor Hugo had sunk down and only part of him was being seen. This wasn't known to the artist until the curtain was pulled and the journalists all came in. Rodin, of course, was shocked and mortified and didn't know what to say. Before he had a chance to say anything, the praise started. What a magnificent conception - Victor Hugo rising out of the slime and corruption of our times. He was wise enough to keep quiet and if you go today to the museum in Paris, you will see Victor Hugo rising out of the slime and corruption of the 19th century. And I thought about Whistler, who once painted a portrait of a wealthy lady. When he finished, the lady's husband said, "That's not really a great work of art" and Whistler said,"Sir, I am sorry to tell you your wife is not a great work of nature."

Well, none of these seemed particularly useful for my theme today so I looked in the dictionary and there I found that the definition for State of the Art is the current level of sophistication of the developing technology and this at least gives me a starting point to talk to you about.

In terms of the physical and mechanized aspects of what we are trying to do about disability these days, we are in a very advanced state of sophistication in our technology, our knowledge and our skills. Our main challenge is simply to get the knowledge and skill and capability out and apply it to the millions of people around the world who need them. We are in a situation where we can get equipment that will enable someone with a single breath to activate and control a wheelchair or a television or a door or whatever this mechanism happens to be hooked up to. But at the same time, we spend hurricanes of breath on speeches like this one and we are still not able to guarantee the integration of that person into the society in which he lives. We cannot guarantee the protection of the most elementary human rights for that person. And that, my friends, is the problem that I think we must be dealing with and it is why conferences on the subject that you are going to be talking about are so important in moving us ahead into a solution to the problems that we are all talking about. I am sure you have heard some eloquent descriptions already of what the problem is and it is, perhaps, my function to try and give that a little international connotation and try to bring to you some of the things that we have learned from the world level that might be helpful to you.

The International Year of Disabled Persons has certainly succeeded in focusing attention on the many problems in which we are interested and putting the subject on the world agenda. There is no assurance that it is going to remain there, however, and that is our big challenge as we look to the future. We had many, many meetings. My travel agent tells me that I have already traveled more than 120,000 miles this year in the pursuit of IYDP, and I will probably do that much again before the end of the year according to my present schedule. But it won't be worth it unless at least some of these meetings result in something that is going to keep happening; result in changing the situation; introducing new elements into the situation and doing it all in a way that lasts. So I tell every group I talk to it is wonderful to get together, it is wonderful to learn that we share our enthusiasm and our concern, but the thing we must be thinking about is what can we decide and talk about that is going to continue and going to have a real meaning in terms of people and their lives.

When we start to examine the real dimensions of the problem of disability, we usually start by asking how many are we talking about and I can give you some numbers that will emphasize the position that we cannot be satisfied with what we are doing. But before that, I would like to approach the question from a slightly different direction. Before asking how many seriously disabled people there are in the world, I would like to talk a moment about how many seriously able people there are in the world. Unfortunately the statistics in this area are not very good and I have not found any way to get reliable data about the number of people who are without a flaw, the ones who have 20-20 vision, perfect IQ, no problems with their liver or kidneys, no aches in their joints or bones, no overweight, no high blood pressure, no hang-ups about anything, who are nimble, strong and filled with social and physical grace. As I look around me, including looking in my mirror, I have to conclude that there aren't very many people who are perfectly able. I suspect that it would be generous to estimate that 5% of the population would fit that factor. So we must conclude from that that some 95% of the population is less than perfect. Does that mean that they are all disabled? Well, we don't say that because that is not the way that we define it. We reserve that term for certain categories of physical or mental impairment and for the real or imagined consequences that we think are identified with these certain categories of impairment. We have evolved some standards which vary in some degree from society to society, that select out of all of the potential combinations of physical and mental variations some that we label "disability". Too often the real functional limitations that may or may not accompany the individual condition are given less weight in the selection process than are the stereotyped assumptions about these conditions. A bookkeeper and a football player, each having lost a leg, are both designated as being disabled. A football player, forced by high blood pressure to refrain from football, is not called disabled and there are endless combinations of this kind that we can demonstrate.

It must remind us that the estimates that we use about the prevalence of disability always rest on a pattern of still logical judgments based in large part on the stereotypes of history as much as on the objective situation. Surveys by Rehabilitation International, the World Health Organization, and a number of national authorities, have produced data that justify, as a rough indicator of the prevalence of disability, the factor of 10%. Some recent studies of the situation in areas in the earlier stages of economic and social development, where the main causes of the impairment are the least controlled, have concluded that it must be assumed that least 15% of the people in such areas will be disabled. These figures may be difficult to accept because the reality behind them is often not easily perceived, but I can assure you that our own investigations in the field have given us evidence to know that they are the reality. This means that there are more than 500 million people in the world today who have a significant disability. These cold and awesome statistics should lead us to many lines of thought. Perhaps the most important is the realization that behind the numbers are people, each of whom has a particular set of problems as a consequence of one or more impairments and of the way society has reacted to their situation. There are retarded children who are penned up like little animals. There are deformed men and women begging in the market. There are people of enormous talent who, because of blindness or deafness, are engaged in menial tasks. There are young people who cannot go to school. There are elderly people whose lives are ending in solitude because they are rejected by their communities. There are literally tens of millions of different situations and we must never make the mistake of thinking that we are talking about a homogeneous group of people who are the disabled. We are talking about more than 500 million individual people, each of whom has a disability and each of whom has many other things; a family, traditions, customs, tastes and appetites, fears and apprehensions, pride and ambition and a vision of life as he or she would like it to be. The statistics help us to understand how much waste of talent and energy there is when these millions of people are denied the opportunities available to others in their communities and what a drain of resources there is upon the millions of families and thousands of communities in which disability occurs and the demands of time and energy resulting because of this. The accumulation of costs and the losses of human potential which may be traced to disability is staggering and is as I have stated earlier, an important obstacle in the process of economic and social development.

I'd like to say a little bit, apart from the numerical aspect of the problem, about the character of the problem or the nature of the problem bearing in mind what I have just said that there is not the problem but there are many millions of problems made up of complex situations. But we have to agree on what we are talking about so we agree that we are talking about people with - but with what - and we can't find a very easy way to say what it is that we are talking about. We have some catch words, but what is the meaning behind them? I suspect if we even made a list among this relatively erudite group, we would end up with many different kinds of lists and many different categories of the kinds of thing that we are talking about. I think, in this connection, the recent decision by the World Health Organization to establish a hierarchy of terminology to be used in this field is very helpful. It doesn't matter whether or not we agree with the use of each individual word because this tends ot vary in different countries, but the hierarchy of definition is important, I think, in analyzing what it is that we are really talking about. If we analyze each problem as we are thinking about it in this context, it helps quite a lot to clarify what the real problem is. If we see that you can have an impairment, but it doesn't happen to limit your functions in a given category of life, then you do not have a disability. If anyone who has that impairment is stigmatized in a particular society, you are handicapped, but your problem is not your impairment. Your problem is society; so you can analyze the situations in this slightly over-simplified way and at least find out what it is we are talking about and what it is that we have to do something about.

If we return to the football player and the bookkeeper I mentioned earlier we can see what I am talking about perhaps. They both have an impairment, each has lost a leg. So far as his work is concerned, the football player certainly has a disability. So far as his work is concerned, the bookkeeper doesn't have a disability because he doesn't need his leg to keep books. As far as society is concerned, they are both handicapped because anyone who has lost a leg is handicapped, regardless of whether it has a functional implication on life. The ball player with high blood pressure has an impairment, he has a disability, but he doesn't have a handicap because we haven't yet started stigmatizing people with high blood pressure. This, perhaps, will give you some idea of how I think we can use this hierarchy of thinking to understand each problem as we come to it.

There are, of course, individual problems that we must analyze in that way and there are the problems that society itself has in a collective sense because of the existence of disability affecting a large number of people. This creates social problems in terms of the inability of some people to participate fully in the life and activities of the society and the effect it must have on the morale of any group of people who deny the rights of participation of some of their members. It creates economic problems in that there are people who become dependent families because of the disability of one of the members. There is the loss of productivity that we suffer on the part of the people who could be producing and on the part of the people who must take care of the people who could be producing. And there is the drain on the economy of our present system of providing so much care without so much real involvement and opportunity for participation. There is a political problem of considerable dimensions although it hasn't really yet manifested itself in very many parts of the world. But mainly because of the energy and activity of disabled people themselves, I think this is something we may anticipate for the future as becoming a much stronger political force. We must realize that we are talking about at least 10% of the population as being directly affected. A United Nations group estimated that, if you count family members and others who are involved in reacting to the problem of disabilities, we are talking about 25% of the population who are directly or indirectly affected by the existence of disability. There was an article in the New York Times this weekend in which it was estimated that, in the United States, we spend more than 30 billion dollars a year in disability benefits alone. This is Workman's Compensation and Insurance and all the various acts that pay just benefits. We are not talking about rehabilitation or education or any of the positive steps, but just the benefits - more than 30 billion dollars. Well, even if it weren't a Reagan administration, I think, when we are talking about something that involves 30 billion dollars, 10% of the population directly, 25% of the population indirectly, we have the nucleus of a political issue, I am afraid it will have to become one before we can get everything done that should be done.

A successful response to this problem requires that we take action in both of these broad categories of problems, that it is necessary through rehabilitation services and through legislation, regulation and services of any other kind, to help people who have disabilities qualify for full participation in the community and the society in which they live to make them able to play their part in this integration that we are really talking about. But, equally, and perhaps more important is that it hasn't had as much attention. Yet, we have to help society adjust itself to this situation and play its part in making possible this integration that we are talking about. In an effort to reach some world agreement on how to go about this dual effort that I am talking about, Rehabilitation International, over the last three years, prepared and drafted a Charter for the 80's. It looks like this and I put some copies back on the table if you want it. This resulted from consultations all around the world with disabled people in their groups, with government agencies, with professional people, with volunteers, anyone who had a concern about the problem. It represents a very broad consensus that has a tremendous level of agreement by all these groups in all parts of the world. It is far from a perfect document, but you can never get a perfect document when you have that large a committee. The important thing about it is that it was agreed to in the end by a great majority of all these people and groups around the world. The recommendations are boiled down to four aims really. First, we must do everything possible to make sure that the preventive services to avoid impairment happening reach all people and all families. Second, we must make sure that the necessary rehabilitation and support services reach everyone who needs them. Third, we must do everything we can to enhance and encourage and facilitate the full integration of people with disabilities in their societies. Fourth, we must make sure that the necessary information is distributed and reaches people in a way that is effective and digestible to them in coping with this problem.

These are all regarded as being equally important and very closely interrelated objectives and the charter goes into some detail in giving the background of each one of them, the theoretical base for it and some practical suggestions and then in the end it has targets for action in each of these areas; at the local level, at the national level, and at the international level. We hope it provides the kind of framework for everyone to think about what they are going to do after this year in order to realize the benefits of whatever enthusiasm we have engendered.

In keeping with my time promise, I am not going to talk about all four of those aims, but I would like to say a few more words about the last two because I think they are especially relevant to your work here - the integration objective and the information objective. When we talk about integration, we are using the word in its pure meaning and I think it is important to be clear about this because this poor word has been beaten to death over the last two or three generations as we have used it to describe every kind of civic problem whenever any sort of difference is around. The pure meaning of the word "integration" is bringing together the parts and making a completeness out of them. I would like to think of that as what we are trying to do when we think of integration of disabled people and their communities - not into their communities, but the integration of disabled people and their communities. We must help disabled people themselves become capable of participating in their community and we must help the community become capable of participating with its disabled members. What we are talking about is bringing these two parts together and creating a completeness that will realize the value of the participation of all of its citizens. There are many things that have to be done to achieve this, of course. We have to assure physical access. We have to insure the possibilities of mobility. We have to insure the possibilities of communications to those for whom that is a problem. We have to insure participation when there are barriers that are other than physical. But in the last analysis, the thing that we must do in order to make all of these things have any lasting meaning, and the thing that I think we have been least able to do as yet, is to get people to change the way they behave. In order to get people to change the way they behave, we have to find a way to change their attitudes. We do not know very much about how to change people's attitudes in a really scientific and cause and effect way.

This leads me, however, to the next question of information because that suggests a route that we might like to take in this regard. It's tempting to think, and I'm afraid much of what we all do is based on this temptation, that if we can just get enough information out, if we can get enough films and enough on T. V. and enough printed and all this kind of thing and get enough people to be exposed to it, that this is going to do the job; that this is eventually going to change their attitudes because it is logical that they should change their attitudes and once their attitudes are changed, obviously their behaviors are going to be modified. Unfortunately we can't find any evidence that that happens. There have been some very careful studies of this question by some of the major psychological institutions around the country and there is absolutely no evidence to prove that you can change people's attitudes sufficiently to change their behavior simply by letting them have different information about the situation about which you are talking. There have also been some studies that have shown a little better results in terms of the effect of studies that have shown a little better results in terms of the effect of experience. That is, the experience of living in a contact situation with people with disabilities, and some studies have indicated that this has produced some favorable results in some people. But of course, if we think a moment about history, we realize that many millions of people, who for millions of years, have had disabled people in their families, in their villages, in their communities, and are the bearers of all the prejudice and discrimination that we are trying to modify. Not only the people who are living with the disabled people, but the disabled people themselves also have the misunderstanding.

We did a study two years ago for UNICEF, the UN Children's Fund, about the situation of disabled children around the world. In the course of this we visited the most remote corners and jungle clearings. We talked to people at every level and every society, from the disabled child or the parent in a small village up to the Minister of Health or the International Economic Development Planner. All these people have one thing in common, which is a dismal amount of ignorance about disability, what it really is, what causes it, and what you ought to do about it. So I think that they suggest that, if we can devise a way to produce a combination of these two patterns of communication, the information that people need to understand, in their mind, why this situation must be changed, and also the practical experience with it so that they ingest it in ways that we don't really entirely understand yet from a communication point of view. It is obviously something deeper and more effective than just reading or looking at a film or watching television. In order to do this contacting and giving this experience, we, of course, have to find ways to do it in a natural way. It does not do any good to pass a law that everyone has to spend three hours a day with somebody who is disabled. This would likely make the situation worse and this is what is really important about the things that we are doing. Laws are necessary for spokesmen for disabled people to have their voice in the councils of our organizations and governments. This means that people are going to be interacting in a neutral context. They are going to be talking to each other, not about the disability problem, but about the problems of the school or the work or of the organization of the government. I think that that suggests a tremendous potential for it and the whole business of mainstreaming. This is what you are here to talk about. It is important in itself and it is important for the disabled people. I think it is equally important because it will create a new experience for all of us for everyone in the community, the people who have the prejudices and discriminations, the people who are called disabled, the people who are not called disabled. They all need this new kind of experience and if they get it and it is reinforced with the right information, then I think we may be on the right track. At any rate, from the information that I have, and looking at the situation from many different countries, I think that this approach offers the best hope for bringing together these disparate parts and creating that completeness that we were talking about.

Apropos to this last comment, I am reminded of the fact that I was talking with our Camp Director the other day and he advised that they had fourteen hemophilic youngsters, who are under the supervision of the Long Island Jewish Medical Center, at camp this summer for several weeks. They were placed through all the cabins with the other children. The only thing that was provided by the hospital was a certain measure of medical supervision. They had a great time. Apropos of your point, the children, who were not so disabled or so impaired, also had a great learning experience. I guess that this is the more important side of the equation at this point and time. Thank you very much.

Your chairman has suggested that if you have any questions, I would be glad to answer them.

Dr. Nesbitt, who used to be associated with us back when we were the International Society for Rehabilitation of the Disabled, and therefore referred to as the International Society. It is now Rehabilitation International. He has indicated that there were interesting things happening in other parts of the world in terms of sports, activities for school leaders, youth movements and mainstreaming and asked if I would, in thirty seconds, summarize for him. That's not a terribly fair presentation of what he asked, but that's the subject.

I think the most impressive thing that I can say about that is that we are more and more seeing that while it is beneficial for the different countries to know what is going on in other countries and see how it might fit in your country, the direct translation of things is often very difficult.

Sweden is looked to as sort of the practical example where they have achieved a very high degree of integration and a very high level of services and a very active role is played by disabled people in their organizations in the community in general. In the first instance, and I don't mean to belittle what they have done at all, but they have a very small population, a very homogeneous population and is a very prosperous country. They haven't been in war for a long time and they have had a high level of social security for 50 years. So it is wonderful that they have had the concept, but it was much easier for Sweden to do than it is in most other countries. It is interesting to me to find that people from here or from the United Kingdom or from other countries that go there, the disabled people that go there to see how this type of integration is working find that what one is talking about, in terms of independence of living and participation, etc., is quite a different thing. For example, in the United States independent living, a great deal of emphasis is put on the right to choose where you are going to live and to decide for yourself what community and what part of the community and all this. This is a choice that nobody has in Sweden. They have a very tight housing situation and it is almost impossible for anyone just to decide they are going to move because there just isn't any place else to live unless you have made a long preparation for this in terms of your job and somebody else is going to be moving out of his place and what not. It has never occurred really to the disabled people in Sweden that this freedom of where to live is very important. It is not anything that is important in that society. That is just one example of what I think when I say experience is very translatable as long as we are aware that it is going to be different and we look at what is done in one place and try to apply it in a way that will be relevant in our own community.

Another very interesting example of accomplishing what I have been talking about is the PHAB movement that started in the United Kingdom and you are lucky enough to have the director of that movement here participating in discussion. Thisis a bringing together of disabled people, disabled young people and young people who are not labeled as disabled,to engage in all sorts of activities. It has caught fire all around the world. I think it takes a little different form, as I have just said, in terms of the different cultures, but everywhere I have seen it, it is doing a very good job of this combination of information and experience that I was talking about.

INTERNATIONAL OVERVIEW: STATE OF THE ART

Concurrent Groups

#1 RECREATION/LEISURE

Facilitator: John Nesbitt
Recorder: Mary Essert

We had a very large group. There were 40 people and obviously, the topics ran from A to Z. The discussion was very stimulating, there were many comments, discussions, problems and solutions. A few of the concerns were as follows:

The definition of mainstreaming came up several times and we all had different interpretations. One definition was offered and we are not saying, this is it, just point out that this was one of the definitions offered and the definition is, "To get the disabled to live the same life as the abled live."

Another concern related to identifying and reaching the population with the program. There were concerns, there were some answers to that.

Another concern was funding; how to do it, where to get it, etc.

There were many successes and accomplishments shared by the resource people, most in the very positive things. Some information was shared which I am sure helped others in the group.

#2 SPORTS ACTIVITIES

Facilitator: Julian U. Stein
Recorder:

We went into a definition of "Sports" and we decided it was any kind of physical activity based on the individual's choice and also it had to involve some kind of physical conditioning improvement to health and body.

We discussed the desire for mainstreaming. The first preference expressed, especially by those who had some handicap, was to be mainstreamed whenever possible. We realized that there are certain activities with limitations and in that case they should be mainstreamed to the maximum extent possible.

We talked about goals in sports and decided that the will to win was all important. Winning is always not important, sometimes it is impossible, but striving to win was the important feature. We talked about the competitive spirit and pretty much decided that the competitive ability and desire depends upon the individual, but that it is healthy for everybodv to have some competitive desire.

We decided to define mainstreaming and what it meant to us. One of the key things is the least restricted environment which in sports should be made available to the maximum extent permitted by the disability. The mainstreaming should be a continuum from specialized programs for handicapped to totally integrated programs where the handicapped can participate on an equal basis with normal participants.

We talked about the desire for integration. This varies with the individual, but the consensus in our group was that most people wanted to be integrated to their maximum capability.

We talked about ways of educating the public. One of the things we discussed was the publicity of spectacular achievements by handicapped people and we talked about the reverse mainstreaming which is taking a few able-bodied people and integrating them into a program which has previously been only for handicapped.

#3 REHABILITATION PROGRAMS

Facilitator: Earl Cunerd
Recorder: Marjorie Murphy

The group discussed what was going on in the agencies and our concerns about three of them I think are very important.

One point discussed was the changes of attitudes and the new awareness on the youth or the disabled; being aware of how we ourselves look at disabled people, etc. We discussed education of communities and agencies and the disabled themselves and their families.

Another point discussed was the early admission of children, preschool age and infants, into mainstreaming and how that impacts on the lives of the families and educating them.

We discussed the importance of the involvement of the disabled in all facets of planning and administration of the programs which impact their own destinies, accenting the abilities and not the disabilities and the need for knowledge and mainstreaming in the preparation and training of people who work in rehabilitation and agencies and hospitals, etc.

The group felt there was a need for them to express a resistance to any further 'labeling', no matter how well intended it is.

Another stimulating discussion was around the rehabilitation of people into the work force. In Sweden, after the person was rehabilitatied into the work force, the government still provided assistance wherever necessary; sometimes re-evaluating his whole situation and having the person start over again. We, as a group, felt it would be desirable in this country to also have that type of support for persons once they were rehabilitated.

#4 VOCATION AND CAREER OPPORTUNITIES

Facilitator: Paul Hippolitus
Recorder: Susan Bowers

Most of our discussion revolved around the need for more preparation, especially when getting disabled people into the job market, and the fact that there is very little participation of disabled youth in career preparation and training. I would say that, generally, for all youth, there is not much of that, especially in schools. We talked about the fact that many times the disabled people are not trained in a field or are not given the opportunity to be trained in a field where there are jobs. Somebody brought up the fact that they can get training in Greek, but they are not getting training jobs in computers where there are jobs. We talked about how youth agencies can help because often they are linked with such programs and certainly in the case of the Red Cross and other youth agencies, there are a great deal of volunteer opportunities. We also discussed the need to access disabled youth to get them involved in these programs where they develop leadership and skill development, career experience.

We talked about attitudes, how people, able-bodied people, have low expectations of what disabled people can do. Often it becomes a self-fulfilling prophecy that if somebody says they can't do something, they just think they can't and they don't.

We talked about outreach and how that is important to reach schools and families and pull together many resources in the community.

We talked about accessibility, physical and programmatic, in terms of employment and a range of program options.

Transportation was one of our big discussions, the cost and the need for it.

We discussed disabled consumer input to the decision making process of planning programs.

#5 EDUCATION/FAMILY

Facilitator: Judy Hoyt
Recorder: Elizabeth Munz

Our group, as its number one priority, felt that agencies must tell their story to others in the community. Many of our agencies do offer services. It was decided they needed visibility, telling people what they are doing and what they want to do. The suggestion was made that there should be a directory of all agencies so that these agencies could network locally.

A second priority was the need for attitudinal workshops which would change people's attitudes. They would include both disabled families, families of the disabled, and non-disabled families so that there could be exposure.

Third, was the involvement of parents and again, involving parents of disabled children with parents who do not have disabled children so that they could share and understand situations.

Jack Dinger's workshop came up with four items that they felt were necessary: One key item was exposure. People could think about things, but when exposed to a disabled person, as an individual, they would experience each person as a human being and an individual rather than as some thought.

Let's get into action and not talk so much.

Parents of the disabled do need to play an advocacy role. They need to be involved with their children.

The disabled students themselves must advocate for themselves. They also must educate others.

International Overview: State of the Art

Prior to the time that we broke up into small groups, statements were made by international resource persons; particularly people from Mexico, from England, Philippines and Hawaii. The one point that I wanted to repeat had to do with a definition which Bill Suzuki shared with us having to do with yesterday's discussion in arriving at a definition with the persons who are from Taiwan and from Japan where there was no direct translation available at all. Those persons, by drawing pictures, came up with a definition which reads this way, "Working cooperatively and continuously with existing organizations for the disabled in expertise, planning, facilities, financing, etc." I think that is worth sharing. The other resource persons who shared from the other countries gave us some super materials to talk about and think about as we then divided into these mini groups, one of which was entitled "Health and Safety." We would like to include the safety record of mainstreamed children and children in camp settings.

Interestingly enough, there were two groups which had to do with attitudes which came out as subgroups in order to really let everyone have an opportunity to talk. I will read the first statement which had to do with consumer discrimination. "Attitude change can only occur through positive interpersonal interaction by promoting opportunities for the disabled and the able bodied to come together on equal terms. The barriers of fear, ignorance and prejudice can be destroyed. This process must be followed to effect attitude change in three areas:

a. Negative attitudes which exist between and among groups of disabled consumers.
b. Negative attitudes which exist among able bodied towards the disabled group.
c. Parental attitude change is an area which merits special attention. The overriding issue must be a systematic approach toward attitude change as a major special issue through needed and experiential approaches.

The next group had to do with attitudes of parents, particularly, and those needs which parents face. One parent was in attendance in this group and one youngster, who has parents, was in this group so we had an interesting input. I think the principal point had to do with education in general and had to do specifically with education of the parents and their own attitudes. When to show them and when not to show them in order that potential may be reached and risks may be taken and successes may be felt.

The second point had to do with professional guidance people and some of the negativism that has been felt and a need for more positive approaches.

The third had to do with the society and the education thereof, again, and attitude change. We felt the charge to agency personnel had to deal specifically with providing opportunities again in which people may interact, in which parents, students, children, disabled, abled, everybody may react together in order to provide those opportunities for trust building and risk taking so that children may reach their potential.

Keynote Speech

By

Harold Russell
Chairperson
The President's Committee on Employment of the Handicapped

I think this is kind of a turning point in our nation in the cause of the interest of our handicapped population. We have come a long ways. I can well remember back in the days of WW II, back in 1946 and 1947, when the main or the cause of the handicap was certainly not one that was well supported. In any way, either in the industry area or government area, or the private sector, or even in the community life of our nation, it was our common wish and desire for too many of our people to put handicapped people in institutions or at the very best, hide them away in the house and as a result there were a vast number of people unseen and unheard.

If the President's Committee on the Employment of the Handicapped did anything, it awakened interest and support in the cause of the handicapped. The Committee, as I said, was instituted by Harry Truman in 1948 to promote the cause of employment of qualified handicapped people. At first it was only physically handicapped people who were hired and it was successful relating first to disabled who were returning from WW II and, secondly, from the civilian population. We soon found that the numbers of our handicapped people in the normal civilian life in all parts of this nation were far greater than the total numbers of those that suffered disability on the battlefields.

It became obvious that cause and support was not all that was needed. It became very obvious that handicapped persons could not move around in society, could not move in the employment area, the social area, the churches and synagogues of our nation. They could not participate fully in the community life. So a federal law was passed, back in 1958 or 1959, which decreed that all federal buildings be accessible for the physically handicapped. Not very long after that all our states, in one way or another, took up the same law and made state laws which said that accessibility was to be the key word for our handicapped population.

I remember when President Eisenhower came to one of the annual meetings of the President's Committee to make a special presentation to a young marine in a wheelchair. When it came time for this young marine colonel to come up to the podium to receive his award, he could not get up and four members of the Marine Corps Band had to lift him up on their shoulders and bring him up to the President of the United States who said in effect, "It's kind of tragic here today that this young Marine who has given so much for his country has to be carried up to this podium to receive an award from the Commander in Chief and it is a shame that he can't wheel up under his own power."

Needless to say, it was not very long before those architectural barriers came tumbling down and they have been tumbling down throughout the years. Today we see parking spaces for our physically handicapped, we see curb cuts, we see automatic doors and we see all kinds of conveniences which make life a little easier. I am not insinuating, in any sense of the word, that this battle has been finished because it has not been finished. We still find churches and stores and businesses and government buildings that plainly say "no" to our handicapped population who can't come in because, very simply, they can't get in. The fact remains we have moved forward, moved forward in a kind of miraculous way because we are changing the architecture in this country to make sure that a very large population is included in the kind of program that says, "Yes, you can come in here. Come in here, you are welcome."

When Jack Kennedy came into the White House in 1960, the program was bent further to take care of not only the physically, but the mentally slow and the mentally retarded. There were many people who believed, and certainly those in the field of rehabilitation, that a mentally retarded person could not take his place, especially in the employment sector of our nation. We soon found out that a mentally retarded person placed in the right job for the most part, with the proper rehabilitation program, can do that job as well and sometimes even better than our so called "normal" individual, if there is such a person. And so once again the barriers came tumbling down. The Federal Government directed a program for the employment of qualified mentally retarded people and today there are more than 17,000 mentally retarded people working for the government and it is no secret that their employment record is as good and sometimes even better than the so called "normal" persons. And so we have moved forward in all these kinds of areas.

In 1973 the Magna Charta for the handicapped people of our nation was passed and reformed the Rehabilitation Act which directed that special contractors, recipients of federal funds and the federal government itself give equal opportunity to qualified handicapped people. I would like to say that the increased numbers of handicapped people dramatically increased as a result of these laws. Unfortunately, this was not so, but the fact remains that the doors have been opened and so-called medical examinations and pre-employment examinations, which virtually excluded qualified handicapped people from employment, from education, now have been removed and certainly these areas are now more accessible for handicapped people than ever before. I think this is very important for the very simple reason that the numbers of handicapped populations are dramatically increasing.

We talk about our young people and we see the wonderful work that our organizations have done here tonight. YMCAs, the Boy Scouts, the Girl Scouts and all the other fine national organizations are now engaged in this wonderful program, Project MAY. We see that the young population of our handicapped population has increased dramatically. American Medical Association tells us that between 15,000 and 18,000 young people between the ages of 18 and 29 each year become victims of spinal cord injuries as a result of recreation accidents, automobile accidents, skateboards, diving, Saturday night specials, motorcycles. It has taken a tremendous toll of many of our young people who live their complete life in a wheelchair. So it is completely necessary and important that we use the force of our organizations to integrate them into their organizations and their various programs.

I think one of the great programs that I am excited about is that the President's Committee each year has a writing contest conducted in public schools in which we bring to Washington, each year, the fifty winners from the fifty states. There is a two-day program which is sponsored by the labor organizations which exposes these young people to some of the problems of our young handicapped people. It seems to me the great national resource of our nation is our young people and it seems to me that we have to direct our attention and support to bringing these people into the actual management and support of all these various programs. Yes, I think that the kind of organization, the kind of work that you folks are doing is of tremendous support.

Harold Russell

I was impressed to hear that the number of handicapped Boy Scouts is over 15,000 here in Greater New York. If this is true in New York, think of the avenues that could be opened in our various organizations throughout this great United States of ours and it seems to me that all of us can be just a little prouder tonight. We have helped and are helping support a program that would bring into the mainstream some very worthy young people, people who need our support and our help. We are not going to help the handicapped, what we are going to do is help the handicapped help themselves.

I do not presume to speak for handicapped people, but I do believe that if they were allowed an opportunity, many of them would express something like what I am going to read to you now. This was written by a young man who came to New York, who was born without any legs, who found it difficult to get through high school and college. Finally, by sheer perseverance, he overcame all these odds and became a great leader in the field of rehabilitation, in the field of education. He wrote something like this which has always been an inspiration to me which, hopefully, will be something that all of you can support.

> "I do not choose to be a common man. It is my right to be uncommon if I can. I seek opportunity, not security. I do not wish to be a kept citizen, humbled and dulled by having the state look after me. I want to take a calculated risk, to dream and to build, to fail and succeed. I prefer the challenges of life to the guaranteed existence, the thrill of fulfillment to the stale calm of utopia.
> I will not trade freedom or my dignity for a handout.
> I will never cower before any master nor bend to any threat.
> It is my inheritance to think for myself, to stand erect, proud and unafraid, to enjoy the benefits of my creation and face the world boldly and say, 'this I have done'."

For our distinguished visitors and for all of you, this is what it means to be an American.

MAY New York Congress
September 11, 1981

CULTURAL UNIVERSALS IN MAINSTREAMING

By
John A. Nesbitt
President, Special Recreation, Inc.

We are talking about the system today and various systems, etc. I would like to share with you something I ran across the other day on how to get along in the system.

If it rings - put it on hold
If it clanks - call the repairman
If it whistles - ignore it
If it's a friend - take a break
If it's a boss - look busy
If it talks - take notes
If it is handwritten - type it
If it is typed -copy it
If it is copied - file it
If it is Friday - forget it

It is Friday, but I hope we all work at remembering and why, because we are about something that is very important. We are working at opening up youth service to people who are disabled and we have to remember as many things as we possibly can. Now I would ask you please to get out the goldenrod paper that was in an envelope that was passed to you this morning, because in a little while we are going to be talking to that goldenrod sheet of paper.

Some preliminary comments that I would like to make. One of the questions that came up in our work group yesterday was about the activities that are appropriate for a particular group of people with disabilities. I think I would go back to the end of WW II when veterans were coming home with various disabilities and people were concerned about employment and they came up with the idea of certain occupations for certain disability groups, etc. Since WW II a great deal has happened and we have long ago abandoned the idea of particular occupations for particular disability groups and I think the same idea applies to the area of recreation. There is no partciular recreation activity that coincides with any particular disability group and the thing that we really try to do is to adapt or modify activities so that they are meaningful, enjoyable and fulfilling and so that they keep the challenge, keep the satisfaction, but there really are very few activities that are closed because of any disability or handicap.

Another question that was starting to surface was, "where can we get more information about programs and how to do and where to do, etc.". I would cite three major sources. The MAY Project here - you are in touch with Grace and you have her address, etc. You can direct any program questions that you have to her. You are being exposed during this meeting to the American Alliance of Health, Physical Education and Recreation materials that were prepared and compiled by Julian Stein and they are inexpensive, so that you can look through some of your materials or contact Julian Stein for a wide array of program materials, activity materials, etc. Some of the material that we have passed out this morning has a couple of names and addresses that I will point out to you relative to the information that is available and sources of information.

The first 75 years of the 20th century have witnessed an extraordinary evolution in the role performed by people who are disabled in society. Extraordinary advances in medical science and rehabilitation have made it possible for many people to recover from illness and injury and to recover functioning. Further extraordinary advances and special services such as education, employment, recreation and other fields have made it possible for many disabled people to resume near normal lives with families in the community. 25 years from now we may regard the last 75 years as the rehabilitation era, but we are moving into a new era, and there are still some problems with this new era. There are two situations that confront us. First, the situation that confronts us today may be characterized as the fact that those disabled leading near normal lives, would have their lives become more normal lives if the community at large would accept them more fully and strive to work with disabled persons in overcoming disabilities.

Second, for those persons who are more distant from leading normal lives, for whom disability has been more of a barrier to mainstreaming and for whom prejudice is a greater problem, it is even more important that the community at large make a greater effort to accept the disability and to work with the person in overcoming the disability. There are a number of people who have been a part of this rehabilitation era - disabled persons, parents, professionals and volunteers in rehabilitation. I call them rehabilitation workers. During the rehabilitation era, they have developed marvelous skills in facilitating the functions of people who are disabled. They have also developed a set of attitudes that go along with involvement in the rehabilitation. They are not negative attitudes that focus on disability and incapacity. They are positive attitudes that focus on disability and incapacity. They are positive attitudes that focus on ability. We may have moved from the rehabilitation era into the mainstreaming and normalization era. It may be that the point in time has come when the community as a whole, and the agencies that serve the non-disabled, will become active participants in the new era of mainstreaming and normalization. It may be that the positive attitudes toward people who are disabled and seek to incorporate those special rehabilitation skills into their work and dealings with disability and dealing with people who are handicapped in one way or another.

This rehabilitation of disabled of the last 75 years was culturally universal. It happened throughout the world in all nations and all countries. The mainstreaming and normalization era that I feel the next 25 years will bring is also universal. The International Year of Disabled Persons helps us to look beyond our local and national boundaries. It helps us to realize that illness and injury are universal. It helps us to realize the rehabilitation of the disabled movement and the mainstreaming and normalization movement are universal. They are cultural universals. We thank our co-workers from the United Kingdom, Mexico, the Philippines, Sweden, and other countries for bringing us living proof that mainstreaming and rehabilitation are universal. Everyone here should seek an opportunity to exchange ideas with our international visitors. These exchanges can start simply in asking them how they might have solved a problem that you have. I have always found international exchange a great stimulation and a great motivator. The other affirmation of cultural universality of rehabilitation of the disabled and the mainstreaming movement comes from those international statements of human rights and social goals that have been adopted by the United Nations. The following statements deal with the recreation dimension of life, but the statements in their totality deal with all aspects of living and with total rehabilitation - the medical, social, educational and vocational as well as recreational aspects of rehabilitation.

I break rights into two categories. First, in this context, the human right means a social standard that has the allegiance of enlightened citizens. Second, and this is in contrast, is the civil right which is enforceable, a statute that can be affirmed in a court. The first general statement is the United Nations and universal declaration of human rights. Article 24 states that everyone has the right to rest and leisure including reasonable limitation of working hours and periodic holidays with pay. Article 27 says that everyone has the right freely to participate in the cultural life of the community, to enjoy the arts and to share in the scientific advancements and benefits. Moving on to a statement by the International League for Mental Deficiency, which has been endorsed by the United Nations, this is the declaration of general and special rights of the mentally retarded and includes the following article: The mentally retarded person has the right to live with his own family or with foster parents to participate in all aspects of community life and to be provided with appropriate leisure time activities. If care in an institution becomes necessary, it should be in surroundings and under circumstances as close to normal living as possible.

Next the United Nations Declaration of Rights of the Disabled Person. The General Assembly of the United Nations in Article 9 states, "disabled persons have the right to live with their families or with foster parents and to participate in all social, creative or recreational activities. No person, no disabled person shall be subjected, as far as this evidence is concerned, to differential treatment other than that required by his or her condition or the improvement which he or she may derive therefrom. If the stay of the disabled person in a specialized establishment is inaccessible, the environment and living condition therein shall be as close as possible to those of the normal life of a person of his or her age." The Declaration of Rights of the Deaf/Blind Person, article 8, states that, "deaf/blind persons shall have the right to engage in leisure time recreational activities which shall be provided for their benefit and the right and opportunity to organize their own clubs or associations for self-improvement and social benefit." The United Nations International Year of Disabled Persons plan of action states, "the purpose of the year is to promote the realization of the goals of full participation of disabled persons and integration into society. These concepts should apply in the same manner and with the same urgency in all countries regardless of the levels of developments. Societies have an obligation to make their general physical environment, their social and health services, their educational and work opportunities as well as the cultural life including sports, totally accessible." From UNESCO and its international charter of physical education and sports and with a certain amount of thanks to Dr. Carl Troester, who is the director general of the International Council for Health, Physical Education and Recreation, is the following statement: "Special opportunities must be made available for young people including children of preschool age, for the aged and for the handicapped to develop their personalities to the full through physical education and sports programs suited to their requirements."

Cultural Universals in Mainstreaming

These various statements by the United Nations and a specialized agency and related non-governmental organizations attest to the fact that rehabilitation of the disabled and mainstreaming and normalization are cultural universals and we are participating in a cause, a movement that is worldwide in its significance and goals.

Please, if you would, take up your yellow covered sheet and in that turn to page 1. A number of the speakers have presented their concerns about attitudes - the negative attitudes toward people who are disabled. I have attempted, for my own understanding and perception of this situation, to poll from some of the writers and researchers some ideas that seem to me to have validity and I think that in the first section here dealing with attitudes, negative syndromes and acceptance, I have tried to state as clearly as I can the fact that we are dealing with a desperately serious and profound problem. It is very simple to say attitudes, negative attitudes, and just pass it off, but I don't think it helps us to really look at how deep the problem of negative attitudes is, their source and their impact on a continuing basis. I have made a number of generalizations.

The first is about society. The different in society, and this is the way society views people who are disabled, the different in society are less desirable. Negative characteristics create negative attitudes. The public's unconscious attitudes toward the disabled is negative. I think this points out how hard we have to work when we have to start to deal with attitudes. We can't simply pass it off at a meeting and say, "Yes, we must deal with attitudes." We have to sit down and really address this fact on a continuing basis - day in and day out and never give up the effort to change the public in general and people that we meet on an individual basis, etc.

Now regarding the facilitators. None of the disabled decide who may join at school, at work, at recreation. This is something we have got to bear in mind. Many professionals perceive low confidence among the disabled. The way I am using the word professional here, I am talking about the middle class which in western society is the very large group of people who make decisions about school, etc., but this middle class largely has the perception of people who are disabled as being incompetent and this undermines all kinds of positive things that we want to see happening to the disabled persons. The adjustment of the sheltered person is undermined.

Next, one's adjustment is dependent on attitudes of others. Finally some things that I believe are true I see are reaffirmed in the literature, and I think it is an important comment about the dimension of recreation. Recreation is a good thing unto itself. We want it to be worthwhile and meaningful and fun, but also many of the recreation activities that we have undertaken for those goals also have a tremendous impact on the public. I am talking about our sports program, our arts program, etc., wherein the public has the opportunity to an enjoyable voluntary contact with the disabled person which increases favorable attitudes. An enjoyable voluntary contact with disabled persons increases favorable attitudes. Higher frequency in contacting disabled increases positive attitudes. Closer contact with disabled persons increases acceptance.

I see a cycle of prejudice or a cycle of acceptance and we have to figure out a way of breaking into that cycle of prejudice which leaves people out and change that into a cycle of acceptance that brings people in. In a somewhat sarcastic or humorous vein, I have tried to characterize the syndromes, the attitudes that I think I have run into in talking with some supervisors or administrators. For instance, the leprosy syndrome, I think is a real thing. "If I touch them, I may get it." These conditions, like paraplegia, are contagious. Some people think this. The deuteronomic syndrome, "They must have done something wrong. God means them to be punished. If they repent they will get well." We can put this aside and say that is pretty funny, but the fact is that many people feel this way and the fact is that the guilt that people feel when a disabled child is born into the family or when an accident takes place, is a very deep gut level reaction. "What did I do wrong that I am being punished this way?" So some of this psychology is operating in the way that people react.

On down to some of these others which I think I have encountered and I think you have encountered also. One of the things that I have come to is we become really tired of focusing on the disabled person, the handicapped person, the disabled, the handicapped and what not and I am always, as you are, terrifically impressed with the handiness of people, the cleverness of the ability of people who are disabled. When you look at the definition of mental health, I think it is very interesting that among many people who are disabled, the mental health is really excellent as far as the general population is concerned. I see so many things, as you do, that are very positive from the population that is supposedly disabled so that I personally have come to see people as being handi-people rather than as disabled people. Over the years, in working with students and with the public, etc., I have developed for myself a formula that I think works in changing attitudes from being negative toward being positive towards disabled. My formula which starts with information, goes on to stimulation, then identification, then an initial exposure which must be a very positive exposure of a group or an individual to an individual who is disabled, etc.; and then to more intense, more frequent and larger groups of exposure. For instance, an individual experience would be having a lecturer come into a class, speak on disability and speak on his or her own disability. A larger experience would be for the students to go to Special Olympics or to a sports event or to a President's Committee on Employment of the Handicapped banquet. That's my formula. I think it is your job, each of you individually, to come up with your formula that spells success. If you will turn to page three in this outline, I have tried to compile for you some checklists on universal dimensions of standards of living that coincide with these cultural universals that you might want to consider in working goals and identifying problems in mainstreaming or normalization. That is the first thing that shows up then in your universal dimensions of standards of living.

Next in direct service and in new direct services for administrative and supervisors, here are some ideas or here are some areas and functions that might be considered in developing programs and services. If you turn on to the next page, page 4, we conducted a project called the National Institute on Special Recreation over a three-year period involving hundreds of leaders in recreation for disabled persons. Through this project and various activities, we came up with approximately 34 goals that we are pursuing during the 1980s and 1990 period. As you are working in your work group sessions or as you are back in your agencies or what not, you might consider some of these goals. For instance, the #2, the accountability of recreation services of handi-people. That might be accountability of your particular agency to handi-people or the acceptance and advocacy, etc.

Next on page 5 are guidelines for the development of recreation and service. You might find this helpful in considering the overall development of a total program, a total involvement of your agency or program in service to people who are disabled. On the next page, page 6, I simply want to point out to you that this is what we call inservice training and there are a number of pre-service training programs providing training and recreation for/with people who are disabled. Page 7 is a very brief description of our special recreation.

The next page starts out with publications released by Special Recreation, Inc. I would like to point out to you that we put about 2,500 pages in the ERIC System which means that they are on microfilm in 700 libraries across the country. Those titles which you see there with the easy number, if you identify an ERIC Library, you simply tell the librarian this is the number of the document that you want and they will provide it to you. You have to find your ERIC library, tell them the ERIC number. It is an easy number and they will give you the document on microfilm and if you want any part of it, you could photocopy it.

We have a question about federal funding and #4 there is federal funding on recreation. On #9 you will find information resources on special recreation. That lists about 75 sources of information on recreation for the handicapped including Dr. Stein's Information and Research Utilization Center which opens the door to thousands of pages of information and materials.

Next is our Credo and then finally the green sheet is the suggestion looking back thirty years to the first recreation graphic which Mr. McCahill and Harold Russell were responsible for publishing in 1951 and reminds us that we should also be planning and looking forward to the next 30 years. What are things going to be like in mainstreaming and normalization for people who are disabled thirty years from now. When we search for the essence of conscience-izing as an emotion to direct us, we may find that we have entered an era when the entire nation is able to say, "We accept you," to people who are disabled. Maybe mainstreaming and normalization is accepting people for their positive traits, for expressing that acceptance to a lot of mundane things; things like including someone in a program, giving someone a lift in a car, taking a few extra minutes to hassle a wheelchair, saying a written communication, writing a verbal communication, breaking a supposedly complicated process into sequential tasks. Accepting people may be going to the trouble to foster a set of attitudes that allow people to join, to learn, to work and to enjoy. It is not that much to ask of the AA's (the automatically accepted) on behalf of the AR's (the automatically rejected).

COORDINATING RESOURCES

Concurrent Groups
Feedback

#1 Recreation and Leisure

We looked at community organization as vital and considered the networking effort as being very important. Then began consideration of resources, their import, further that key personnel who were creative and had vision had to be there and were extremely important to the whole effort in recognizing the creative aspect in the use of the already existing resources. We agreed largely that political involvement is important whether we like it or not, whether it is our thing naturally or not. In regard to community funding there were three good points made particularly from Gerald Fain and from the experience in England. Great care in fund raising must be taken to avoid any approach of the sympathy bit and I think this is probably something that we would come back to over and over in our individual presentations as well as in our oral and in our daily - you know, putting our bodies where our mouth is as far as effort.

The second point was that the activity involving both the disabled and the abled community be focused as an activity shared and that fund raising then can be accomplished more effectively in that way. Think of programs first, not funding first. We went on and did talk some more about resources, about starting points, and again, where to get those opportunities and where the creative mind is to grab and to look and to act. We had some very fine personal exchange in the group and some good soul searching on behalf of a number of us at that point. I think that the total feeling that came out out had to do with accepting one's self before it is possible to reach someone else in order to be active on behalf of whatever recreation and leisure time activity is being considered. "The whole will produce more than its parts." A very important statement. We did reach consensus on that. We are each other's resources. More than dollars, more than anything else, we must begin with commitment. Start small, generate confidence in small successes and the bottom line is "Me." I begin with "Me."

Basically our group went over different resources, places and people you can contact. We started talking about government and tied it in a little bit with what Janet Pomeroy had discussed, how politics are so important. We talked about school involvement, using the youth serving agencies in networking collaboration, disabled consumers themselves, industry, working with them. We discussed using people in in-house organization as resource people. Meeting people at conferences such as this, we have all had time to chat with each other and learn what each other's expertise or field of interest is. We listed a number of them, resources, people to contact.

#2 Sports Activities

There were two or three major areas and then we have three recommendations for your consideration:

One of the major areas that was discussed was in terms of resources and the importance of people. The key resource, to have success in programs; is in the involvement, the interaction, the cooperative relationships of people including leadership. A key point in involving consumers and also the lay public.

Coordinating Resources

There was some discussion concerning the importance of developing interactions and truly cooperative relationships among the many groups involved in sports for the handicapped. Before these groups can interact with the general government bodies of sports at any level, whether it be state, national, international; the special sports groups have to get their act together and work as a cooperative whole. An example of this was the national governing body in the U.S. to basketball. The National Wheelchair Basketball Association is now a part of ABUSA which is the governing body for basketball in the United States. Also, examples were given of how, in other countries and particularly Canada and England, much of this is being done in terms of the national governing body making modifications so that those with disabilities can participate.

There was some discussion concerning finance and particularly some of the exaggerations that continue to be made regarding finances or financing programs so that those areas which do need additional funds can receive greater priority. There was concern about the growing backlash that is happening in many areas, particularly as federal, state and local funds get cut more and more and have to be channeled into priorities. There is a need to recognize that this is going to be an increasing problem in the United States for at least the next three, four or five years.

The recommendations that were made are:

1. Having increased involvement by the youth serving agency with and in school programs. While an excellent job is being done in many places, there are many places where it is not being done.

2. Make more innovative and effective use of funds which provide assistance and ideas to help communities.

3. Use of sports, recreation and physical activities as an important means of creating a positive awareness not only in schools, but through our communities regarding the abilities of those with handicapping conditions because of the universal understanding of accomplishment in sports and physical activities.

#3 Rehabilitation Programs

We basically discussed attitudes of the providing agencies and felt that the attitudes of those working for providing agencies should be altered in a more positive direction. In addition, the clients themselves may have negative attitudes about their abilities. We discussed the socialization of the disabled and how they can be given the feeling that they can have a good future or a decent future.

We discussed the competition between the agencies and felt that the providing agencies should confer with one another for the benefit of the clients rather than to propagate and perpetuate their own organizations. We discussed many things and our discussion became more conversational and enjoyable and productive, of course, but basically we felt that the attitudinal change, this attitude change with the client and the providing agencies will enhance the attitudinal structure throughout the community.

Coordinating Resources

#5 Education/Family

1. Change attitudes. Start with young kids and their families through school, books and media, simulations, face-to-face contact and using mainstreaming as a way of changing attitudes of all.
2. Family education and support for families who have and families who do not have members with disabilities.
3. We need a united front with consumers in key positions as consumer and advocacy groups, government, schools, and others who work for common goals.

Russell Hoyt

What mainstreaming means to me is to have any person - able bodied or handicapped, it doesn't matter - integrated into a program with other able-bodied persons or with handicapped people or having a handicapped person come into the able-bodied group. It doesn't matter. It is just having someone come into a new program and having experiences that they have never had before or just to have someone get experience and to know how and the knowledge of what they are trying to do. Do you agree with that Ricky (Hoyt)?

THE UNITED KINGDOM

by

Elizabeth Dendy
The Sports Council, London, England

You have probably noticed that there has been a small group of disadvantaged people with you this week. We would probably have called ourselves disadvantaged or maybe even incapable, but you have all been very kind in sharing what we all like to call a common language. When I received a program from Grace Reynolds and I saw the word 'mainstreaming', I went straight to my dictionary. There was nothing about mainstreaming, it doesn't exist in the "English", so I thought, "Well, I'll leave that one." So I then went on to moderator and I discovered that it was a Presbyterian Minister presiding over an ecclesiastical body. Perhaps you are an ecclesiastical body, but I am no Presbyterian Minister!

Perhaps the differences in our language do help us to re-examine what we are saying and what we are doing. Perhaps the differences in our situations again stimulate us to consider what we are doing, to look at our own situations and see how much we can learn from other countries. Certainly, I know I speak for us all here in how much we have enjoyed and appreciated and learned from what we have heard is happening in this country. I think the best thing I can do is to, in looking at our future strategies, speak very briefly about how we in the Sports Council do include any sort of physical activity. We are talking about things like bird watching, keeping fit, movement and dance for very elderly people as well as all athletics. We, in the Sports Council, have an on-going campaign called "Sports for All." We are more concerned probably with participation than we are with high level competition in sports.

It seemed appropriate that when it came to IYDP, and here again we have to be different; in the United Kingdom, we changed that and we call it International Year of Disabled People. We felt that word was more in tune with our way of doing things than persons. We decided that our campaign for this year would be sports for disabled people. You have seen one or two of our posters. We then looked at the aims of our campaign and, really, some words I think during these two days, must be wrung to death, but that was that they have such importance that I don't think we need to worry about that.

The first of our aims was awareness, we could call it attitude, making sure that everyone appreciates the value of physical activities to people with different disabilities. This comes out in funny ways. I tried, in directing this campaign, to see that we brought it in as many different and varied agencies as possible with some unexpected results. I wrote, amongst otners, to our Royal Air Force Sports Council and the next thing we knew, all our regional offices were being rung up by the local air stations saying, "What can we do to help." I had visions of the whole of the Royal Air Force rushing around helping with our campaign. Our aim is making everyone aware of the fact that people with disabilities can take part and can enjoy physical activities. In some cases more of them will be given the opportunity and it is creating the opportunity that I think is important.

The United Kingdom

Our third aim was integration, joining in with so-called able-bodied people. Again, it is another word that has been flogged to death during this year and could be interpreted in so many ways. This is our nearest equivalent to mainstreaming, but it really comes out in more ways than just taking part. It means that the opportunities are available to everyone. We talk about community provision for sports and the facilities are available for the whole community and disabled people are a very important part of that community, but can we make sure that they are able to integrate and use the community resources, the community facilities and wherever possible can they take part in their activities with able-bodied people?

Julian Stein mentioned earlier that in our working party yesterday we were talking about the role of the able-bodied sports organizations and we were trying very hard to encourage them to take responsibility for everyone who wishes to take part in that activity and everyone includes disabled people. So that when it comes to training instructors, training coaches, they are also concerned with the slight modifications that might be necessary to train disabled people, particularly a special area of sports and that is in this whole field of water sports. They are developing very quickly now and in an exciting way in our country so that we get our Canoe Association to feel completely responsible for any canoeist; be they blind, be they amputees, be they a paraplegic. We like to hope that soon we will reach the situation that any Canoe Club in our country will be able to welcome any people with disabilities, that any disabled people who want to train will be enabled to do this through the coaching structure of that sport. Integration is an enormous task, but it is one that we are working toward. It is not the only answer and I think in the area of competitive sports there is very much a place for segregation for competing with your peers.

This leads me on to the last point which is involvement. By that we mean involvement of people with disabilities, first of all in choosing what they want to do. It is no good for us to tell them what they might want to do. We must reach a situation where they can choose what they would like to do given the opportunity where they can organize their own activities and can take the lead in deciding. Now this is generalization. Everyone we are talking about, some of the people we saw in Janet's film, will not get to that stage, but where this is appropriate, we must give them the opportunity to take the lead and play as full part in the organization of that activity. I think one very good example here would be the film, Not Just a Spectator, some of you saw last night.

We have a very remarkable man enrolled in our water sports for disabled people. He chairs our committee, he holds the highest qualification in coaching sailing in our country which means that he is responsible for the training of other coaches. He is an expert dinghy sailor, cruisor. He trains rescue operations for sailing. He happens to be a paraplegic. Now that is incidental; he is a sailor first and foremost. He is unusual, but as much as possible, we should persuade disabled people to play a full part in the organization.

Obviously, our problems are very much the same as are our aims. How far we will be able to carry them out is up to us. It is people, it is us who can assure that this happens. The structures of IYDP will go after the end of the year. The public interest will inevitably wane. We will be working up to the next international year and there are many people who will say, with relief, on December 31st, "Good, we can forget about that now." If we do not achieve our aims, we have failed because IYDP is only a very early start. Perhaps our first aim is to change attitudes because once we have people's attitudes going on the right lines, we should be able to continue.

Those are our aims and it really is people who are our main resource. Service, it is up to us and most people involved in recreation are extroverts and enthusiasts. We enjoy what we do and surely fun and enjoyment is the main thing worth striving for. Why do we wish everyone to have the opportunity of taking part in some activity? We have a big task ahead of us and one of our main aims and, probably you have the same one here, is the problem that we have of a complex situation, of many organizations involved, not always very happy to cooperate with others. I am sure we are not alone in having certain petty jealousies among small organizations who really do not want to share their expertise and knowledge, but we must achieve communication so that we are not fragmented, but we can share our experiences and the things we discover. We all know what each other is doing and we can work together. Only in that way can we achieve our aims.

THE UNITED KINGDOM

by

Terry Thompson
Director of PHAB, London, England

You and I have a responsibility for each other. I believe that God has chosen to work by using us and by saying, "I will achieve things by using people." We have this tremendous opportunity so what I really want to do is talk about what we are trying to create together in this mainstreaming.

I would like to talk about specific things that are happening in the United Kingdom and through PHAB, but I will be negative and talk about trends which we have experienced and which worry me. I hope to say four things I hope we will try to avoid as we go back and look at planning, developing implementing, promoting and evaluating mainstreaming which is what it is called on the top of this piece of paper.

The first is to recognize very clearly that in any mainstreaming program we cannot expect mainstreaming to happen overnight. We cannot suddenly defeat the years of history that have isolated disabled people from the community. I think we have seen many experiences in the United Kingdom where somebody has said, "Yippee, its IYDP", or some other phrase. "Let us bring disabled people into our programs." They throw open the doors and they have taken a couple of people in wheelchairs and they have taken them into the room and, of course, nothing has happened or many things have happened. There has been embarrassment and misunderstanding and those people have gone away and never come back.

I think, if we recognize that disabled people have been isolated from the community and the community is ignorant about disability and we really take seriously the fear and the embarrassment and the ignorance and the misunderstanding; then we will understand the need to go slowly and to actually create what we call, in PHAB, a "half-way house" situation. Here disabled and able-bodied people meet each other and share interests and share activity and can begin to overcome their own personal hangups and worries whether they are disabled or able-bodied. Is there anybody here who is going back to look at a mainstreaming possibility within an ordinary youth provision. I would want to say very strongly, please see the need for a half-way situation where you can bring people together where they can gain the confidence in each other to go into the community and into the normal activities where we believe it is the right of disabled people to be.

A second trend that I see in the United Kingdom that worries me a little bit is that we should not be thinking about creating a leisure program for the disabled. That may be a strange thing to say in this conference, but I am going to repeat it because I think it is important. We should not be about creating a leisure program for the disabled. What we should be about is creating the support that makes it possible for disabled people to create their own leisure programs.

The United Kingdom

I believe that leisure time is free time and doing what I want to do. That may be to go to the church or go to a blue movie. It may be to be with my friends or it may be to be on my own. It may be to be very active or it may be to be drunk every night and beat myself to death, but leisure is freedom and its choice. I think that too often the trend is that we produce the program which we believe is right for disabled people and then we say, "Here it is. Aren't you lucky, come and enjoy it." Now that is not leisure and, to me, it isn't mainstreaming.

I believe that there is tremendous support needed to get disabled people, whatever their disabilities, to the positions where they can exercise the same sort of freedom and choice that we have, but I believe that is the part we will be following. While I see the value of leisure in terms of rehabilitation, in terms of therapy, in terms of muscle control and development, please let us remember that leisure is about fun, leisure is about free time and doing what we want to do because we enjoy it. If these things happen, great, but the prime purpose is what I want to do with my free time and that is the choice. That is what we should be offering to disabled people.

The third trend is that no leisure program involving disabled people, no mainstreaming, can guarantee participation, friendship or acceptance. I think there is a situation and my apologies to the disabled people who are here, but I think it needs to be said. I think there is a situation where disabled feel that in PHAB we can guarantee them friendship. If they come to a PHAB Club, they will find friends. We cannot create friendship for other people. We can only create the situation in which friendship becomes possible. We can only seek to create a situation where decisions about friendship and acceptance and participation are not based on disability. I believe that one of the freedoms that mainstreaming should create is the freedom to dislike a disabled person because you now get behind the wheelchair and you discover just how obnoxious he is. That is something I think we shy away from. Now I am sure there are times when Dan is a pain in the neck. I pick on you, Dan, because you and I have had some good conversation. I do believe this; that we do not owe disabled people a living, or friendship or anything else. What we owe them, I believe, as an able-bodied person, a temporary or otherwise, is to create the situation where decisions about friendship and participation and acceptance do not depend upon that disability. That is what we have to be working at.

A fourth trend is that we cannot wait until the world is right to see these programs happening. I think this is being said in a number of ways during the conference and again this morning. We would all like to see a totally access-free situation. We would all love to have every building totally available. We would all love to have every program open to disabled people with no difficulty at all, but we are not going to have that situation. We do not have the money nor the resources and if we wait for that, then many of the disabled young people we are talking about now will get old-age pensions before they get the chance to do anything.

I believe that one of the things that we have to do is to use the resources that are there, to use each other. We were talking about this a little bit within the group, but if the only way to get to a pub or a third floor (you know what a pub is - am I talking a strange language again?) the only way to get to a strip club on the third floor is to be carried up three flights of stairs and I am a disabled person. I want to exercise the choice of saying, "Carry me up there, that is what I want to enjoy." Or it could be a church meeting as well, couldn't it? I think using these resources is using each other. It is saying, "O.k., the bus is not acceptable, the bus is not accessible." You may have to put up with a little indignity, but if you are prepared to put up with that, we will offer the resources and let us do this together.

I think one of the great things we have discovered, in fact, is this freedom to work together, to achieve things as a group. It is in that working together that we have learned about each other. We have heard a great deal about evaluation over the last few days. The chairman of our IYDP in England said in his half-term report, "Doing well, could do better."

I think if I have to sum up this conference, if I have to sum up IYDP, our program, myself and everybody else, it would be that. Doing well, we have see where we want to go, but we could do better. I believe that by working together and extending our views and using resources, we can create the society which we all believe is right for people, whether disabled or not.

THE UNITED KINGDOM

by

Richard Morrall
Director of Youth Services, Croydon YMCA, England

First I bring greetings from the YMCA, particularly in the London area of which Croydon YMCA is part and also on behalf of the full-time workers, youth workers in Croydon, and they are all eagerly awaiting my report on this MAY Congress when I return.

I would like to begin with a quote from Prince Charles at the opening of this year.

> "There is a need for much greater understanding of the real meaning of disablement as that understanding is the key to more opportunities and a better life for disabled people. Disability affects us all whether as individuals, members of a family, or members of society and it is not just something that happens to other people. Many of us will become at least partially disabled as we get older. Our mobility, eyesight and our hearing deteriorate. Many disabled people, I always think it is essential to remember this, were perfectly unafflicted until suddenly struck down by some accident or disease. Their main aim is to be treated, above all, as normal individuals with similar feelings to everyone else and to lead as normal a life as possible, even though it may involve a slightly greater degree of risk.

For many years the YMCA in Britain has done work with disabled people and in preparation for this special international year, in the metropolitan region we set up a disabled study group. It has confirmed the belief that there are many people willing to help if only we would let them, at a very little cost except in time, for local associations. The group really set out to be of service to the London area YMCAs in examining the ways and the means of improving facilities and services to disabled people within the YMCA. In order to achieve these aims, it was necessary to find out more about the different needs of the groups of handicapped people who use our building. We must provide a practical idea for the kind of adaptations that may be useful and most needful and really, above all also, to keep abreast of research and developments nationally. Action to achieve these aims and purposes has been in the following areas:

- All the YMCAs were, of course, contacted to take problems they had encountered, problems regarding accommodation and what plans they make for increased need.
- Setting up of the library for information and attendance for as many people as possible at seminars, symposiums. They even visited a German village for the handicapped people.

The United Kingdom

There was quite an elaborate start made and all of the YMCAs, then in the London area, circulated information packs, resource packs and up-to-date information regarding this International Year. A number of voluntary work groups were also set up for a similar agency; The London Voluntary Service Council on specific subjects as access, unemployment, housing, amongst many others.

A recession in Britain is biting very hard into the finances of our local associations and sometimes it is very difficult even to maintain a normal program with the limited income, but it doesn't cost money to care for people. We tried many ways to overcome the problems. There were people and it was up to us in the British YMCA to use them.

Some people say they have too many steps, impossible access, etc. But disablement doesn't just mean only wheelchairs. Disability suffered mentally is just as real as that which is physical. They can be praised and their lives can be enhanced by one-to-one helpers in some of the activities. Ideas that have been introduced include the yoga classes, swimming, encouraging the disabled to play musical instruments. Some of our hostels have beds fitted with special devices to enable deaf people to be accommodated.

There is other work that has been done in area colleges. We don't only look really within the closed doors of the YMCA. Look outside in the world around us and ask what are we actually doing to help. We have a scheme that started in Croydon called "Crossroads" and it also functions in other areas. It helps families look after a disabled person for the night while parents are able to go out and relax without worry. There are many disabled who we would welcome as regular visitors. People who have suddenly become disabled, through an accident, may need counseling and this counseling technique, whether it is disabled or able-bodied is something we place great stress on amongst young people in Britain.

These are just some of the ways we show an interest; group counseling and through the work that we are trying to do. I am a great believer, myself, in training and I think it is an all important part and it is vital in working not only with the handicapped, but with any youth groups to develop understanding of each other, of each other's feelings, through the experiential learning situations. I feel this is one of the key methods in developing a two-way awareness and sensitivity, trust and empathy of persons and sometimes we have to put ourselves in another person's shoes to actually feel what it is like to be without.

Disabled people are like any others. They have to face the special difficulty and it is really up to every individual to make the effort to try to understand his difficulties. It is up to the community, as a whole, to respond to the needs of its members, healthy and handicapped people alike. This autumn time we renewed our challenge to local associations to look at themselves to ask questions to see what increased use they can make of the disabled people to integrate them into their membership and into their program and to create a feeling of a caring community.

The United Kingdom

Then it is necessary to look at access, making sure that we are able to accommodate. I believe that we have to be positive in our response. We have to examine ourselves continually to see we are meeting the needs of the people around us.

David was a sixteen-year-old, very healthy, very athletic lad. He was one of my personal voluntary leader team back in Croydon in 1974. He used to help with all the youngster activities, with the play schemes and all of the sports programs. One Christmas he began to feel tired and he had this habit of just dropping to sleep. This worried the other leaders and the other young people that were working with him. Between Christmas and New Years he had to be taken to a hospital and 15 months later he emerged from the hospital totally paralyzed from the waist down. That, to me, hit home very hard, very clearly the problems associated with disabled. Not only to myself, but to the other key workers within our own association. This was something very close on our doorstep. It was not happening to other people, but was very real.

I think that this care and concern and understanding is so vital in all the mainstreaming, whatever the work is that we are doing, but we must stimulate the people around us to enable that process of understanding and awareness to develop. Our greatest resource as has been said numerous times, is ourselves. We need to educate the young people about the people around us. I want to quote an expression from the Bible, "Do unto others as you would have them do unto you." This attitude, perhaps, can take away the worry and the embarrassment on our part as well as theirs. It will also make it easier for us all to participate fully and be less hostile in the surge of life that surrounds us.

SWEDEN

by

Karin Odeback-Bagger
County Council Board of Mentally Handicapped, Gothenburg, Sweden

I am a Director of Care, they say. Perhaps my background will give you some other ideas now, I don't know. I will not talk of work at the YMCA, but I am a member, of course, of the organization in Gothenburg.

At first when I heard about this year which the United States had planned, I did think, "Well done." Every single year should be the year for the disabled and when I say that I have been working for 21 years among the mentally retarded, you know what I would like to say with these words. I hope you will try to understand me.

Yes, I am from a very small country which is highly industrialized. Sweden has a population of 38 million and it is recognized as a welfare state which has a great number of social platforms. In contrast to many other countries, Sweden has no general law with the aim of securing the rights of the handicapped person. However, there is one law which provides for mentally retarded persons. It is called 96A and gives the County Councils full responsibility for the mentally retarded children and adults. It is in this field I have been working 21 years. The total number of the mentally retarded people in Sweden is now 37,000. It is 7.9% of the total population. It means that, in all, 23,900 adults then are mentally retarded.

I want to pick up some figures, I hope it doesn't bore you too much. Of these 23,900, 35% of them live in residential homes, 28% live with their relatives, 16% live alone in ordinary flats. 14% live in small group homes, less than 3% live in special hospitals. The number living in hospitals has declined in recent years. There is a suggestion that all hospitals will be closed in a period of five years. Group homes will be set up replacing boarding schools and residential homes for children as well. I mention this only as an example of how we try to normalize the living conditions for the mentally retarded in Sweden. The county of Gothenburg has 2,800 mentally retarded of different ages and with different handicaps who live in the Gothenburg area. The total population in this district is close to 700,000. The land area of the county is about 5,000 square kilometers, the distance between the north and south end of the county is about 220 kilometers, 120 miles. It is a rather big district in many aspects.

As you heard, I am a director of care in Gothenburg. We all have taken part in looking for better facilities for the mentally retarded. Some of the things I would like to mention here are the mentally retarded person should live in as normal a way as possible in their own flats or in small group homes together with no more than three others. When living in a group home, the retarded person should have his own room, we think. In Sweden we strive and struggle for this. It is a question of private life I would like to say. The mentally retarded person should live as normally as possible. Retarded young people should be given the opportunity to try out our activities and decide for themselves as far as possible. The National Board of Health and Welfare in Stockholm is the authority responsible for supervision and planning. The Board has been interested in finding ways to normalize relationships and living arrangements for young people and others as well. It will try to give them a higher standard of living in certain aspects. Today around 50% of the adults in residential homes have their own rooms so only half of them have private rooms, but still we are on the way there.

I have been talking a great deal about buildings, I know, but one of my problems is to create and to try to find new buildings and new circumstances which could build a pattern or try to give the people inside the buildings a better life. Even if the County Councils are responsible for almost all services for the mentally retarded in Sweden, we need help. We do need help, especially for the leisure time and here the organizations come in, and they do. The YMCA in Gothenburg and other organizations are very helpful. They arrange golfing, tennis, recreation during the weekends, etc. The YMCA in Gothenburg plays an important role here arranging a tete-a-tete every Friday for the youngsters. They will assemble around 100 persons every Friday. They are together with the mentally retarded, meeting each other, and finally I would like to say that this is the most important - meeting people, sharing experiences.

CANADA

by

Richard A. Patten
National Council of YMCAs of Canada, Ottawa, Canada

I know that most of you are aware that the country that I come from is a bilingual country and we have two official languages. Part of the problem in our country is half the population isn't aware of that. Canada is a rather strange place and in some ways people know it is a very cold country and we have a fairly small population, but many people within Canada felt we had an opportunity to create a country that can learn and take from our neighbors and from some of our historic relationships so we thought that perhaps it would be possible to incorporate the strength of British Parliamentary system and, of course, the strength of the French cultural background which is so rich, and the organization and efficiency of the United States. It didn't quite work out that way and so at the moment we have a great deal of problems. For example, I just received yesterday, when I phoned my office, a letter inviting me to give this presentation; because of strikes. So our country ended up with the British organization and efficiency, we have inherited the French form of government and, of course, the American culture. We have a rather interesting mix. Because it is a bilingual country, there are two of us who will be sharing in the presentation with you. Myself and Marie-Blanche Remillard who is at the other end of the table. She will be dealing with the important issues, primarily because I am not sure what they are.

One of the many areas in which I am not confident or knowledgeable is in the field of extensive work with the handicapped or disabled. However, in generalities, I can share some information that may be of help as to what is happening in Canada. Our federal government, for example, as some of you may know; is a fairly socialized system in our country primarily because of the size of the country and a relatively small population in relation to that. But out of 24 million people, 9.8% or 2.3 million people are classified disabled. This is a statistic I have from statistics. Here are some of the things that have happened in Canada over its past few years. There has been a change this year, for example, in the Canadian Charter of the human race and freedoms which has included a section dealing with the rights of the disabled. Our Canadian Mortgage and Housing Corporation, the Federal Corporation of the government, provided grants to people who in any way wanted to renovate their homes for access, for developing ramps, widening washrooms, what have you, up to $10,000 per housing unit for anyone who would be disabled in the country. We felt this was quite a good point.

There is also a monthly magazine which deals with some of the issues that people may be facing or some of the programs or projects, but that is what the disabled are dealing with. This is freely distributed to anyone in the country who would like to receive this monthly magazine which will be operated by and for the disabled.

In our country we have to wait and see what happens at the end of this year because then comes the evaluation of what happens, what the implications are. I am talking now on a nationwide basis. Then the politicing really starts because usually there are a whole set of recommendations and when that happens, then the groups start to mobilize. Then the non-government organizations or primary organizations, if you will, begin to cooperate and start pushing for change, particularly in the legislative areas.

The government also has provided and still has various forms of employment incentives and that varies according to areas of work, but if a company will hire a person with a particular disability, then the government will help with training and will help pay the salary in varying degrees. Sometimes it is up to 3/4 of a percent until that person is fully trained to do that particular job and in some cases that may be extended to over a year.

Some of the provinces, also some of us in Canada, describe ourselves as a group of people united by differences. We have a very very strong federal system of provinces. Some of you may have heard that and so there are often jealousies and tension between the federal government and the provincial government, but nevertheless, in this particular year in British Columbia, there was money set aside for organizations that wanted to do something special for this particular year. I might mention one thing I didn't mention that the federal government did. They provided some funds, but they were not to be used. The only groups that could apply for these funds were disabled people themselves. For example, the YMCA could not apply to this fund. It had to be a group of people who said, "This is what we would like to do for ourselves." I think that is a very valuable principle and I think we should probably turn the strategies for the future, probably in the next stage of development, in that process.

The province of Ontario took a strong stand related to public awareness and developed sixty media commercials; sixty one-half hour programs that were aired on television and were part of a travel van in which the schools visited various organizations and the theme that they used in Ontario was "Label Us Able." I haven't mentioned all that organizations have done and are doing across the country. I know most YMCAs are involved in one way or another. We have a federation of YMCAs so we seldom have a 'national program'. That is the same for every association across our country. We have had businesses offer scholarships. The Bell telephone, for example, in the country has offered 25% discount on rates for the disabled from here on. I don't know if that is true also in the United States.

Two events, one in particular that some of you may have seen, is Terry Fox, the story about that young man who was stricken by cancer and lost one of his legs. He was so determined after seeing other cancer patients and some of the other handicapped people, that he decided he wanted to do something to demonstrate the potential capacity. It was in that spirit that he ran half way across Canada, running at a pace of about 26 miles a day. The inspiration that he provided to our country was absolutely incredible. He passed away two months ago. Tomorrow is the first anniversary of the day he had to stop his run because of the reoccurence of cancer and I suspect that there will be millions of dollars that will be raised. Last year he raised over 24 million dollars for cancer research. That's one individual in a country with a population the same size as California and that stimulation, that inspiration, has carried on and will carry on and has changed many people's hearts by a demonstration of things like that.

Canada

I've heard people say, "Change in attitude." My personal reaction is I agree that that is an important thing. There also are, though, I believe, people who have open attitudes. They may be in the minority, those who may be receptive, but are ignorant, and I place myself in that category in that I may be supporting things that I am not aware of and that having been aware, that perhaps can change my behavior. I think there has been a great deal of that this year.

The last comment I would like to say is I came here almost toally ignorant and I leave ignorant. I think I am a little less ignorant. Certainly I am inspired and I say that sincerely by having met some people here who have demonstrated to me the capacity to achieve something that perhaps others obviously have not thought was possible. When I saw the love story of the Hoyt family, that was extremely inspiring to me and I know for other people as well.

CANADA

by

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I work for the YMCA of Montreal and I work for a small branch in the east part of Montreal, that is a French part of Montreal. I have worked there a year and it just happens to be 1981.

I believe I am handicapped. There are things I already know and I don't have to be sensitized. You don't have to become any more aware. That is a problem of handicapped people, at least physically handicapped. I am a community worker. I don't know much about sports, I don't know much about recreation. We are involved in it and we get, as they said, the support for individuals who want to define what they want to do.

What I am more interested in talking to you about is community work. The way I define community work and the way this definition is shared by the YMCA of Montreal is that the individual will get the most and they will be able to do the most after they are involved in the process of analyzing their own situation and finding the solution to their own problems. The YMCA is working with all kinds of groups of citizens and for me, mainstreaming means that you treat a group of handicapped people, physically handicapped, as you do any other group of citizens who have problems and mainly social problems.

As Richard Patton said, we have a very organized public social network and because it was 1981, in a few months there had been a large amount of legislation dealing with handicapped people. Everybody became confused and we got the feeling that maybe all this legislation was not exactly what people needed.

In the city where I work, we were a group of around fifteen to twenty people, handicapped, and coming from a poor background without any college or university education and not being integrated, like you say. None of them work, but they talk together about anything from religion to sexuality to anything that we found out that was their main problem. We found they needed support help. You know if someone is quadraplegic and wants to live on his own independently, he would need someone to help him in the morning and help him in the evening (personal care aid.) It also includes taking the snow from your ramp or cutting the grass and things like that. It is a very large range, support services. I like it.

Montreal is supposed to be supplied by the government and there is no volunteer organization that supply it so people who are not organized depend completely on the good will of and the organization of the bureaucracy to give the kind of service they often need. Everyone knows that they have a problem and they feel they have problems, but they don't know to which extent their problems are shared. The way they worked together was to do interviews of each other; two or three handicapped people going to see others, visit them with a tape recorder and a microphone and do an interview. Questions asked were, "What do you do by yourself?" "What does your family do for you?" "What kind of service would you need?" and sometimes the persons interviewed give very good advice. They say, "I don't need someone 24 hours a day. I need someone 60 minutes a day, two or three different times and my neighbor also needs someone. It is an old person and if we can share the same help, it would be great."

We are building a report and it is going to be an extensive report because it also includes interviews of the social workers and people who work in the community and have their ideas about the kind of services. This extensive report will be given to the Greater Montreal Social Service Organization. We are also in contact with other small groups of handicapped people. We are going to do the same thing in the little area we depend on. This thing, maybe it is going to be a failure. Maybe next year there will be no more support services, but what I can see is that in my little group, in our little group, there are going to be people who know how to work in a group. They have to learn to preside and do the agenda and know now they cannot interrupt. There are physically handicapped who are sometimes socially handicapped. They do not know how to work in a group, no talking anytime, always referring to their own particular thing that happened the morning before and suddenly; not suddenly, very slowly in fact, but if you come each month, you can see different behavior from the people and you see them get more organized.

A conference is planned in Montreal for October by the YMCA which is intended to include handicapped people. The purpose of the conference is to discuss living in the central city of Montreal which has a dense population. Housing, transportation, and quality of living will be discussed. Handicapped individuals will play key roles because they share equally with non-handicapped people in the problems of the inner-city and have the results of their own experiences to contribute.

Representatives in the conference will show that handicapped people have problems like other people and that they are just like others in society and not a minority that is out of the flow of society.

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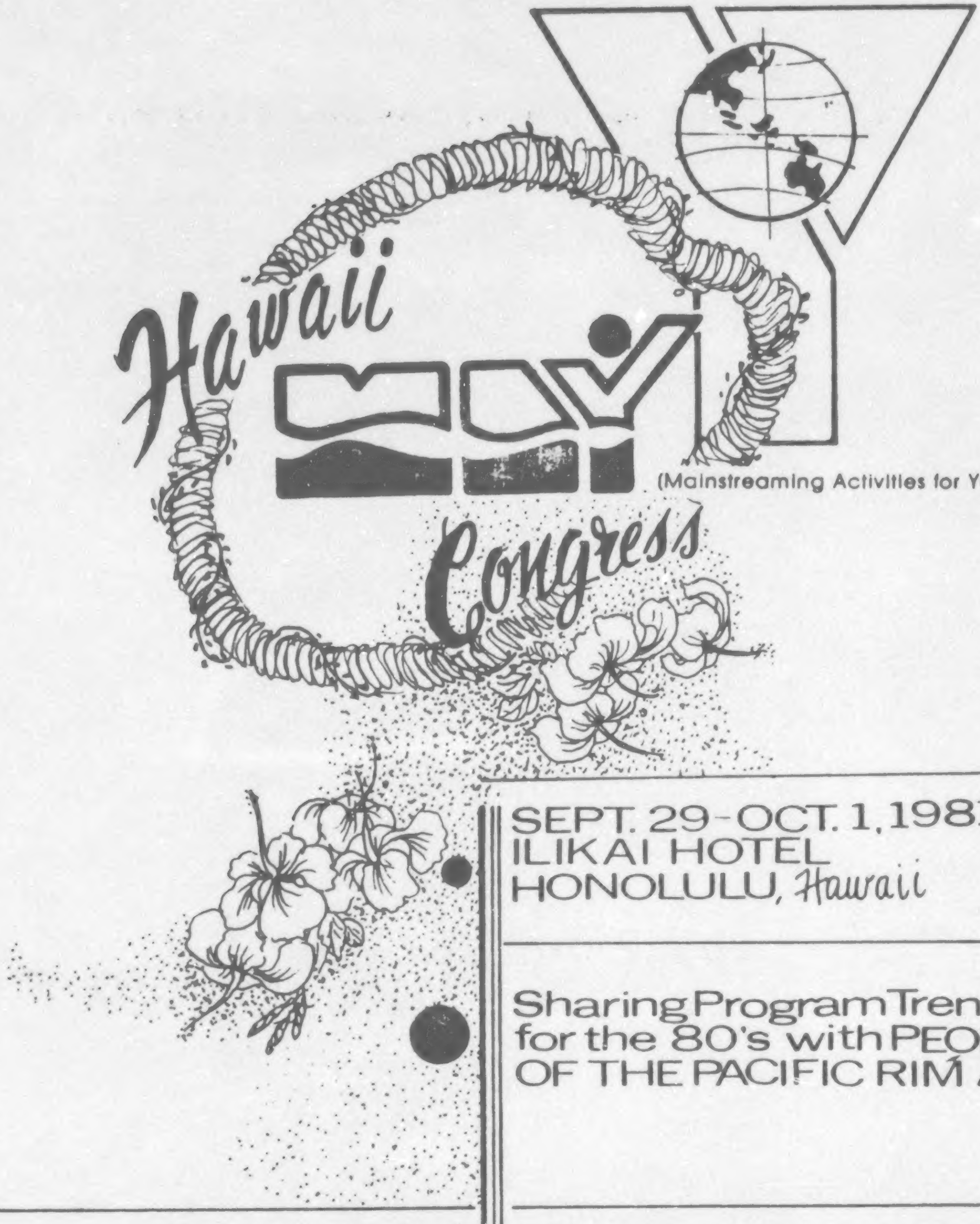
Mrs. Harold Wilke

Hawaii MAY Congress
Sharing Program Trends For The 80's
With People Of The Pacific Rim Area
Ilikai Hotel
Honolulu, Hawaii
September 29-October 1, 1981



Hawaii MAY Congress

(Mainstreaming Activities for Youth)

SEPT. 29-OCT. 1, 1981
ILIKAI HOTEL
HONOLULU, Hawaii

Sharing Program Trends for the 80's with PEOPLE OF THE PACIFIC RIM AREA

IYDP—1981
(International Year of Disabled Persons)
KA MAKAHIKI O KA PO'E 'IMI OLA PONO I PUNI KA HONUA

The Hawaii MAY Congress is hosted by:

- The YMCA of Honolulu
- The Project MAY Agencies and Resource Groups
- The National Board of YMCA's, U.S.A., Program Development Division

In cooperation with the State of Hawaii IYDP Committee

Hawaii MAY Congress

September 29 - October 1, 1981
Ilikai Hotel — Honolulu, Hawaii

PROGRAM

FIRST DAY — SEPTEMBER 29, 1981 (TUESDAY)

8 00 am **REGISTRATION** Pacific Ballroom Lanai

1 00 pm **General Session #1**

OPENING SESSION Pacific Ballroom Pago Pago Room

Presiding
Grace Reynolds
Director of Program Development for
Special Populations
Program Development Division
YMCA of U.S.A

Invocation: **The Rev. Dr. Abraham Akaka**
Kawaiahao Church

Greetings: **Gary Oshita**
IYDP Coordinator
State of Hawaii

Mr. William E. Aull
President
YMCA of Honolulu

THE CHARGE: **The Rev. Dr. Harold Wilke**
Director of Healing Community
Professor at New York's Union
Theological Seminary

PANEL: **Dr. Joy McGehee, moderator**
Special Education
University of Hawaii

United States: **Sharon Bintliff, M.D.**
Director
Handicapped Services Training Program
Honolulu

Asia: To be announced

Pacific Islands: **Dr. Michael Caldwell**
College of Education
University of Guam

International: **Dr. John Nesbitt**
Professor
University of Iowa

3 00-
4 00 pm **SMALL GROUP SHARING**

- **Physical Impairment:** Makaha Room
  Ms. Sally Price, Principal Resource Person
  Community Relations Director
  The Rehabilitation Hospital
  of the Pacific
  Honolulu

- **Mental Impairment:** Molokai Room
  Carol Eblen, Principal Resource Person
  Executive Director
  Mental Health Association
  Honolulu

  Kathleen Wilson, Facilitator
  Executive Director
  Whittier YMCA Service Center
  Whittier, California

- **Sensory Disabilities:** Hana Room
  Colletta Whitcomb Principal Resource Person
  President
  Aloha Council for the Blind
  Honolulu

  Robert Guerrero, Facilitator
  Vocational Rehabilitation &
  Services to the Blind
  Reno, Nevada

4 00
4 15 pm **Coffee Break** Imperial Suite

4 15
5 00 pm Sharing of Disabled Persons Program from
different countries (To be announced)

6 30 pm **Reception (No Host Cocktail)** Pacific Ballroom Lobby Room

Music by: Henry Kaalekahi and Friends

7 00 pm GENERAL SESSION #2 (aloha attire) Pago Pago Room
Presiding
Phil Norris
YMCA of Honolulu — Board of Directors
Manager, E.F. Hutton & Co., Ltd
Honolulu Office

Invocation: **The Rev. Charles Crane**
Church of the Holy Nativity

DINNER

WELCOME: **George Yuen, Director, Health Department**
Representing Governor Ariyoshi

The Honorable Eileen Anderson
Mayor, City of Honolulu

"CULTURAL SIMILARITIES"
Dr. Michael Caldwell

Entertainment **Nora Kurosu, presiding**
Honolulu YMCA Board Member
Assistant Vice President
American Savings and Loan
Honolulu

SECOND DAY — SEPTEMBER 30, 1981 (WEDNESDAY)

9 00
10 15 am GENERAL SESSION #3 Pacific Ballroom Pago Pago Room

Presiding
CDR. Robert C. Pittman (Ret)
Chairman, Commission on the Handicapped
State of Hawaii

PANEL PRESENTATIONS

"Rights and Responsibilities of Disabled Persons"
William Hindman, Executive Director
Easter Seal Society
Honolulu

"Juvenile Justice and People with Disabilities"
Patty Henderson, Executive Director
Protection and Advocacy Agency
Protection and Advocacy Agency
Honolulu

EXHIBITS Molokai

10:30-
12 noon **SMALL GROUP SHARING**

- **Youth Agency Services for the Disabled:** Makaha Room
  Dr. John Nesbitt, Facilitator & Principal Resource Person
  Other Resource Persons:
  John C. Sevier, NERACOSH,
  Boy Scouts of America
  Carla E.S. Tabourne, Program Consultant,
  National Board of YMCA
  John Morgan, Executive
  Tacoma-Pierce County YMCA
  Andrea McLean, Supervisor, Community
  Services Unit, YMCA of Edmonton, Canada
  Hisao Nakamura, Ass't. Metropolitan Executive
  YMCA of Honolulu
- **Therapeutic Recreation for Adults** Waikiki Room
  Robert K. Masuda, Director, Principal Resource Person
  Department of Public Parks & Recreation
  City and County of Honolulu

  Robert R. Dye, Executive Director, Facilitator
  Program Development Division
  YMCA of USA
- **Problems of the Elderly Disabled & Possible Solutions** Hana Room
  Dorothy Devereux, Principal Resource Person
  The Women's Committee of the Presidents'
  Committee on Employment of the Handicapped

  Col. William P. McCahill, USMC, Ret., Facilitator
  Boy Scouts of America
  Scouting for the Handicapped

12:30-
2:30 pm Lunch
GENERAL SESSION #4 Imperial Suite or Pago Pago Room

Presiding:

Fred King
Vice President
Civitans International
Honolulu

Invocation: **Georgia Morikawa**
Director
Deaf Action Group
Honolulu

"COORDINATION OF RESOURCES AND FUNDING"

Janet Pomeroy
Founder and Director
Recreation Center for the Handicapped, Inc.
San Francisco, California

Response:

The Rev. Dr. Harold H. Wilke

2:30-
4:00 pm Sharing of Disabled Persons Program from different countries. (To be announced)

4:00 pm (All recorders will meet with Mrs. Grace Reynolds, Col. McCahill and Dr. John Sevier)

4:30 pm Informal get together Host Suite

EVENING FREE

7:30-
9:30 pm SPECIAL PROGRAM Pago Pago Room

An evening with John & Delores Nesbitt

"A SPECIAL RECREATION FOR PERSONS WITH DISABILITIES; NATIONAL & INTERNATIONAL PROGRAMS & PERSPECTIVES"

(**Mrs. Delores Nesbitt**, Ph.D. Program Assoc.,
Graduate Program in Hospital Admn.,
Univ. of Iowa, and Board Member/Sec.
Special Recreation, etc.)

THIRD DAY — OCTOBER 1, 1981 (THURSDAY)

8:30-
9:15 am GENERAL SESSION #5 Pago Pago Room
Presiding:
Wayne Protheroe
Office of Human Resources
City and County of Honolulu

Summary of small group discussion
Col. William McCahill and Dr. John Sevier

9:15 am Review of the Position Statement:
Paul Kuromoto
YMCA of Honolulu

10:00 am "THE CHALLENGE"
Capt. Gerald L. Coffee
Staff, CINCPAC Flt.
Pearl Harbor, Hawaii

12 noon GENERAL SESSION #6 Pago Pago Room
Presiding:
Grace Reynolds

Invocation: **The Rev. David Kaupu**
Kamehameha Schools

LUNCH

Focus on the Future
Robert R. Dye, Executive Director
Program Development Division
YMCA of USA

CLOSING REMARKS:
Grace Reynolds (Director of Project MAY)
Director of Program Development
for Special Populations
Program Development Division
YMCA of USA

ALOHA!

Hawaii MAY Congress Headquarters
Lanai Room — 2nd Floor

ACKNOWLEDGEMENTS

Our special thanks for assistance with additional funding.

International Paper Company Foundation

The President's Committee on
Employment of the Handicapped

ARCO

EXXON Corporation

Dr. and Mrs. John Sevier

Warner Communications

Other contributors' names were not available
at the time of printing.

Project MAY (Mainstreaming Activities for Youth) is a collaborative Project to assist national youth serving agencies in planning, developing, implementing, promoting and evaluating a collaborative program to mainstream youth with disabilities in regular programs.

Project MAY is coordinated by the YMCA of the USA and is a Special Project of the United States Department of Education, Office of Special Education and Rehabilitative Services, Office of Special Education

Our appreciation to members of the State of Hawaii IYDP Committee members and especially to Gary Oshita, State Coordinator, for their fantastic cooperation

OPENING REMARKS

Robert R. Dye
Director, Program Development Division, YMCA of the USA

It is good to be here today and on behalf of the YMCA of the United States let me also welcome you to this meeting of learning and sharing and planning about how the disabled among us can more and more have open and available to them all that the rest of us have - full participants in what life has to offer.

On September 10-12 a dozen or so of us here participated in a similar conference in New York where we not only had participation from the twelve national organizations who are collaborating in Project MAY, but from London, Mexico City, Canada and Sweden. It was a fine meeting and I am looking for the same kind of happening as we meet here on Oahu in these lovely islands.

What are some of the hoped for outcomes that we might anticipate as a result of our being together.

First, in this International Year of Disabled Persons, we are looking for ways to get the attention of all of our people. So many people are still totally unaware of this issue and they need to know more about this large important segment of our society who live with disabilities.

Second, those of us who represent organizations with programs, buildings, resources and volunteers must learn and we must expand our group of people willing to make this a personal agenda. Speaking personally, I know that too often I have expected one member of our staff, Grace Reynolds, to carry this ball. It must become my job too and the job of others around me. I say systematic because it must be more than a hit or miss proposition.

We need to do some writing about these issues and our organizational and community concerns about them. People will need to know how we feel - what we hope to do. We need to advertise our intent - create position papers - write articles. We need to bring this subject to the surface and not keep it submerged. So the first need for the future is *educating* those who need to know.

Second, we must come to understand that the resources we need to get the job done are close at hand. They are everywhere - present in every community. It is a matter of discovering them and *using* them. I remember in our New York meeting of the MAY Congress one person said, "Unless I can get a grant of some kind, I can't get started in this work." That statement was challenged by a person running a large number of creative programs who said, "It doesn't *start* with money. It starts with a profound commitment to do something - and the programs and the resources will evolve and flow from that commitment." This has been proven again and again. There is great power in an idea expressed with great conviction about a subject that has obvious importance. But *we* must make it happen. Resources do not flow in automatically.

Third, which brings me to one of the most important learnings for the future if we are to advance and make an impact that is felt. The future will demand that we adapt a style of work that is collaborative in nature. You have been reminded that Project MAY is a collaboration of 12 national organizations - a collaboration that began in 1973 because of another issue, the issue of juvenile justice. The success this collaboration had in getting a piece of federal legislation passed by working together - the collaboration for youth, $11 million dollars on youth unemployment. For the last 2½ years this collaboration has been involved together in Project MAY where planning has been done, insights shared, and materials developed.

For an organization to feel that it can go it alone today on an issue as important as this one is, is to be unrealistic. Instead of working in isolation, of seeing the issues from the very limited vantage points of our own organizations, our own environment, our own biases, we need to plan together in the context of the entire community - analyzing together the needs that exist, cataloguing the resources that are available within our communities to meet these needs and to intelligently plan together what we need to do together to attack the problems in systematic and sustained ways. All of us, individuals and organizations, have something to share. We can only realize the power that can be generated by a total approach to these issues when we come together into a collaborative framework. As I said a moment ago, when we advocate for change by ourselves, not much happens; when we advocate together, we can get the attention of people.

Fourth, in my own organization I direct the Program Division and we work mainly in the area of Program Development. Over the next few years we will be making a conscious effort to perform the function that we call "Discovery". There are hundreds of program innovations that are taking place within our communities, in places like London and Hiroshima and Honolulu and Hartford, that have been developed, that we should discover and make visible to all of us. In these two congresses, in New York and Honolulu, I have discovered new resources, new programs, new concepts to use in my own work. Our mutual discovery process in the future should be directed to looking for all the innovative ideas, all the separate parts that exist, and seeing the connections, the wholeness, the integration that exists and can come from the many parts.

For those of us who represent large organizations like the YMCA with programs, resources, holidays, and volunteers, the question before us is how we can really put the disabled on our organizational agendas; recognizing that in so many cases we are the ones who provide the handicaps for people by our unwillingness to open up to them all the opportunities the community offers to the non-disabled. In most cases it is not their problem, but our problem.

We must come to realize that all people have a right to participate in what life has to offer, that those with disabilities wish to participate for the same reasons others wish to participate. And yet, in our ignorance and indifference,

- retarded children are penned up like little animals,
- the deaf and the blind continue to be relegated to the menial task,
- the elderly are shunned and isolated,

and all of this is our loss. The loss of this potential in our society is staggering.

As I have participated in the two MAY Congresses in New York and Honolulu, I remember some words and phrases and conversations that keep sticking in my mind, that give some clues on the future as we determine our tasks and our agenda.

One of these conversations dealt with how we must more than ever involve in our planning and in our management groups, people with disabilities. Terry Thompson who runs an organization called PHAB (Physically Handicapped and Able Bodied) reported in New York of a recent conversation he had held with a disabled person. Terry asked the question, "Do you think your future is being decided for you?" and received the answer, "No, my lack of a future is being decided for me."

Other words I remember:

> "A society which shuts out people is truly impoverished."
>
> "We want opportunity - not pity."
>
> "Resources are everywhere."
>
> "Our biggest problem is not the disabled, but the able-bodied."
>
> "What programs to offer? Anything and everything. Literally anything goes."
>
> "Architecture is important, but attitude is of critical importance."
>
> "The ramp is not enough."

And one speaker who repeated the words of Richard Bach (of Jonathan Seagull fame)

> "If you can think it - dream it - you can do it."

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GREETINGS FROM

Grace D. Reynolds
Director Special Populations, Program Development Division
YMCA of the USA

Let me bring you greetings also from the Project MAY agencies and for those of you who perhaps are not really aware of who we are and how we all came together and formed a collaborative faction. I would like to just list the advisory committee of the collaborating agencies who came together to make this particular project happen in cooperation with the YMCAs of the United States. In addition to these agencies, we have 50 to 75 resource groups who have served in many different capacities across mainland U.S.A., resource groups from the United Kingdom, Europe and Asia. There are many, many people who have been brought together to share, to support in going forth to include disabled people and ongoing programs.

The Project MAY collaborating agencies in the United States are: The American National Red Cross Youth Services; the Boys' Clubs of America; the Boy Scouts of America; Campfire, Inc.; 4-H Cooperative Extension Services; Future Homemakers of America; Girls Clubs of America;Girl Scouts of the U.S.A.; Jewish Welfare Board; the National Board of the YMCAs, and the National Board of YWCAs.

I have a list of the resource groups that we will have prepared for you later, as it is a long one. We certainly thank all of those here in Hawaii who have joined that group, and particularly the IYDP Committee which has worked very, very hard with our site coordinator Bill Suzuki to make this all happen here in the Islands.

It is a rather interesting event when you are working on a Congress in the north in early September and come to Honolulu at the end of September, looking toward the Pacific Rim when you have formerly been thinking about the Americas, Europe and Africa. Without all the tremendous support of people here, the YMCA staff, the University and the various human services delivery systems, of course it would not be possible.

I would like to tell you just a little bit about the project and remind you that in your packets you have the Project MAY training materials that were developed the first year of the project. Everyone on that advisory committee had a chance to tear it apart, put it back together and say, "Yes, this is the kind of material that each one of our agencies can take and use and we can adapt it to our own needs." So I hope you will take a good look at that when you have a chance to look through your packet.

We also want to remind you again that our hope is to share between the United States of America and other countries the principles and concepts to provide opportunities for the impaired, disabled and handicapped to participate in programs and services provided by the community and human services. One of our objectives has been, and I hope we will achieve these, to provide for all who are interested in integration of the disabled the opportunity of sharing information, concepts, practices and materials and, of course, establishing strategies. Secondly, to provide opportunities for cross-cultural exchange workshops which will address issues and concerns regarding the inclusion of the handicapped in regular programs and activities; to describe model programs with urban and rural or farm communities; to review current materials on mainstreaming, or integration, or normalization, whichever you may wish to call it; and at the end of the Congress devise preliminary plans for future activities.

Greetings from
Grace D. Reynolds

There are a couple of definitions that I would like to clarify with you. As we started on this venture and I was meeting people in Europe a couple of years ago, they shook their heads and said, "That word 'mainstreaming' is great for your United States term." The last two years, however, I find it creeping into the languages of the world, so maybe we are exploiting a new word. However, as we talk to people, say in the United Kingdom, they are using the word "integration" and we find this also in South America and many of the other countries. I think this is true, probably, in Asia as well.

The word that was coined in Sweden when we first saw a really good growth in the inclusion of people with disabilities was "normalization" - bringing people to as normal a place in society as possible. Mainstreaming, as with aquatics in our program, is the project that provides skill development, encourages opportunity of choice, and enables individuals to participate fully and successfully in their environments. A brief word of caution. Mainstreaming does not mean that we bring everybody together just because he or she may have a disability and put them all into the same activity or classroom. In mainstreaming we are talking about the opportunity to participate, perhaps at a hospital therapeutic level, in segregated programs. Separate programs where the skills that are needed to participate in programs can best be taught and learned all the way to those who have achieved the ability to participate in whatever activity that they wish and have the right to choose that. That, of course, is the fully integrated or mainstreamed person. We are talking about integration which is a physical, attitudinal, and interacting inclusion of people with differences or disabilities in the environments, programs and opportunities of their choice. We are simply addressing the fact that accessibility is important. Not only physical accessibility, but attitudinal accessibility.

The youth serving agencies and the resource groups who collaborate with Project MAY work together. These include representation from youth agencies, human service delivery systems, ecumenical groups, education, rehabilitation, health, physical education, sports, recreation, therapeutic recreation services and many others. The project is funded in part by the U. S. Office of Education, Federal Education Division. We also have tremendous support from all of our youth agencies, many of our resource groups and there are acknowledgements on the back of your program to the International Paper Company Foundation, the President's Committee on Employment of the Handicapped, ARCO, EXXON Corporation, Dr. and Mrs. John Sevier, Warner Communications and many other contributors' names that were not available at the time this was published. Our sincere thanks to all of them.

INVOCATION

The Rev. Dr. Abraham Akaka
Kawaiahao Church

Our Heavenly Father:

May we thy children, see ourselves in our true proportions.

We are gathered here from many countries to share, understand and gather knowledge for our work that we do daily, the disabled person. If our knowledge is meager, make us eager to increase it; if our vision is narrow; help us to enlarge it. Above all, may we never center our thoughts on ourselves. If our accomplishments are small, may we see the magnitude of the work of others and be strengthened by them.

Help us to make this year and every year to come, the year and years of the disabled person. Give us they guidance, the patience and compassion to do thy work.

Amen.

HAWAII MAY CONGRESS

Welcome

Gary Oshita
IYDP Coordinator
State of Hawaii

Aloha, and as coordinator for the International Year of Disabled Persons, I would like to welcome all of you here today. In our beautiful state of Hawaii numerous private and public agencies have taken part in many tasks in terms of celebrating the International Year, thus helping to create more understanding and awareness of the needs and achievements as well as the concerns of disabled persons. The Hawaii MAY Congress happens to be one of these celebrated projects which I feel can benefit many of you here today.

For your information, this coming Sunday we will be having a Fun Day Jamboree to help celebrate this International Year, another one of our community projects. Information will be out on the tables where you will be signing for registration.

May you all enjoy the conference and for those visiting Hawaii for the first time, we hope you will have a most memorable stay. Aloha.

William E. Aull
President of YMCA of Honolulu
President of the Hawaii Trust Company
Member of the National Board of the YMCA of the USA

One of the nice jobs I have as head of the local YMCAs is greeting people like you who are here for various conferences. It is always surprising to me really how many conferences are held in Hawaii. Somehow we seem to have something out here that brings people to us. Because of that we like to maybe show you why we think we have a pretty nice state to visit.

It is good to see some old friends who have been here; Bob Dye especially, who was head of our YMCA for awhile and is now on staff of the National YMCAs. It is also a pleasure to get to know some of you during this Congress. Looking at the agenda, you have a full one and it looks tremendously interesting.

Very much good luck and have a wonderful Congress.

THE CHARGE

By

Harold H. Wilke
Director, The Healing Community

Thank you, Grace. Grace and I have had a love affair for three years now in our concern together about persons with handicapping conditions. We recognize (certainly I do within the church) that this is a situation that confronts everyone of us. We are working with persons who have various kinds of spiritual, emotional, mental and physical disabilities and problems. In a sense, you see, we are coming to a new kind of oneness. When Dr. Akaka used that word about wholeness, it seemed that that, in effect, said something about what we are involved in here, whether we call it mainstreaming or normalization or a search for wholeness or whatever else it is. This is what you and I are about. It is a joy to be here. I see so many dear friends in the congregation, particularly here with Abraham Akaka who, as you know, is the pastor of the Kawaiahao Church which has been described as the Westminster Abbey of the Hawaiian Islands. I think that maybe that is the wrong definition. It ought to be turned around and we ought to say that Westminster Abbey is the Kawaiahao of England.

We have three days in which we can be engaged in our common task. Our task is that of bringing into the full life of leisure, and that word is used in its widest possible implications, for persons in our common life. It is part of the quality of life that we are engaged in. When the President of the United States said that the 35 million Americans with disabilities constitute our most underutilized national resource, he was saying something we could truly take to heart. In some ways, while we have different points of view on the approach of the present administration, in a real sense we have to say that a new sense of commitment and a new kind of commitment has come in, as we in this coalescing here today of how we may fulfill these varied tasks so that the involvement of persons with disabilities may be a part of our whole program. What I want to do, therefore, is to present what I am calling the seven deadly sins of not involving persons with disabilities in our programs. These seven deadly sins begin in our own thinking and I want you, for just half a minute, to close your eyes and do some introspection about the ways that you yourself have seen persons with handicaps excluded from your organization and to think about the relationship about that to what may even be called a deadly sin. Let's close our eyes and go inside ourselves for half a minute. Yes, we see it in part as a denial on our own part. Yes, we see it in part as embarrassment. Yes, we see it in part as fear and anxiety. Yes, we see it in part as a lack of adequate resources or probably utilization of those resources. O. K. now, open your eyes. Now these are just four that I suggested. From here and there are an additional several that each of you has developed in her own thinking and his own response. We will be doing more of that during the course of these days.

On the plane coming over I talked with a parent who said that her son, age two, was given the wrong medicine, went into convulsions, and after an anguished period of time was finally able to come home. When he did so, he was retarded and without ability to use most of the left side of his body. She said some of her best friends said that this person was a demon and that she had become the mother of a demon. They let her grieve strictly alone. The symbol here is that to which people were responding. They assumed that to be the reality and it was only a symbol that had to do with this youngster. This tragic situation was made more tragic by the response of others.

The Charge

Each of us in our own lives carries those problems and difficulties that we don't want to be reminded of and when somebody does remind us of them, we find it easier, so to speak, to walk on the other side of the street. This is true for all of us. I am not laying on your shoulders something that does not apply to me as well. We have in our office in New York a consultant who comes in maybe once a month, and when Harriet comes with her relatively severe spasticity, her cerebral palsy expresses itself, especially in quite dramatic movements on her part. When I see Harriet for the first time I have to go through that same unconscious process that you go through when you see a person with an obvious physical or other disability. The process of saying, "Is it my reality that I am bothering with here? Is it a symbol here? Or a reality over there on the part of the other person?"

When I see Harriet I know that she is a symbol for me, that the reality is down inside myself. It is one of my hangups, one of my problems that is out of control. I have to have some kind of control. When I think about it, any thought of having control in that situation is kind of stupid, you know. Why would we think of keeping control in a situation like that or in dealing with the seven or eight thousand ministers, which has been my job for 20 years in the United Church of Christ. Why I would need any kind of control is what discombobulates my mind. Yet, there it is. That is my problem. It is my hangup. The reality is in me when I respond to Harriet. Her flailing arms remind me of that fear of loss of control and so, resenting unconsciously and in a sense of consciously Harriet's presence, I don't want to be reminded of this or to have to spend a couple of seconds or maybe even a minute or two having to work through this difficulty.

This is your situation as well when you deal with persons with disabilities. You have inside that anxiety, that difficulty, that problem, that set of adjustments, whatever it is, that says to you, I don't want to deal with this. You can finally get to see it this way. This person out there is really a symbol for a negative reality inside yourself.

Let me share with you out of this something that I prepared last year in preparation for the opening address for the United Nations on the International Year of Disabled Persons. It appeared instead as what I called "The Ten Commandments for our relationship with persons with disabilities". Commandment No. 4 said something about how we see each other with this embarrassment and try to overcome it.

> Fear Not One Another (This is God speaking)
>
> Fear not one another. I know the confusion of your embarrassment, your fears, your anxieties, your brother's handicap. Your sister's disability affronts you. You too are vulnerable. You are both in my care, you are one in my solicitude.

The secondary sin is the sin of negative spread. Negative spread has nothing to do with what happens to your hips after the second dessert. Negative spread really refers to your concept of individuals where you see one disability and you assume, therefore, almost immediately the presence of half a dozen additional disabilities. You see the individual in the wheelchair and immediately you assume something else is wrong with this person. And there is a club, the "What does she want in her coffee Club" coming out of the typical experience of a person in a wheelchair going into a restaurant with her husband and the waitress coming up and saying to the man, not to the person in the wheelchair, "Does she want sugar in her coffee". That is the assumption that so many people make and we all tend to make it. We do it, of course, at the positive level as well. When you see the individual 6'4", broad shouldered and handsome, Brooks Brothers suit, all that, we assume he is the president of his company and a lot of other good things about him. We do it exactly the same way negatively. The sin of negative spread is one that we have to overcome to see, to enrich ourselves, to change gears, to wrench ourselves into thinking, "Here is one thing that is difficult, wrong, negative. What are the positive things?" What are the positive things? The sin of negative spread is the secondary sin of not involving persons with disabilities to find out what their strengths are and not immediately to assume a great many more disabilities.

Thirdly, there is the sin of what we might call the sin of assuming a major difference between ourselves and these individuals - the sense of a major difference in this person and ourselves. During my days at the Menninger Foundation we would hold every Saturday morning a three-hour symposium under the direction of either Dr. Will Menninger or Dr. Carl Menninger. After a one-hour presentation of the patient's situation, the patient would then come in, get a half-hour political walk-through, would resond personally to either these two or other doctors, and then the patient would leave. All of us in the room, 150 psychiatrists and one or two others, talked about the meaning of what had happened there. I remember so vividly that after one patient had gone out, Dr. Carl Menninger said to all of these professionals who were gathered, "You have to remember that there is a very fine line that divides this patient from the rest of you." The sin of assuming a major difference. When an eminent world class scientist, psychiatrist, can say something like this, we have to recognize that there is a very fine line between ourselves and that person over there who is the psychiatric patient in this hospital.

Be grateful for the inspiring quality of life within persons with handicaps which in turn engender within all of you perseverance, humor, coping abilities, patience, and creative victory. But beyond this inspirational thing, you know many persons with disabilities really resent this business of being thought of as the symbol of creative victory and all that. Beyond that, we have to recognize the other which is commonality. Commonality with all the major feelings that the rest of us share as well. Then this commandment goes on, "Recognize in that commonality we all share there is also frustration and anger, anxiety and despair." This reminds you all of the fraility and your common need for salvation and calling to a mission to provide succor and justice for all.

The fourth sin is the sin of making her normal, the sin of making him like everyone else. That is the sin that we take for ourselves when we feel that in order to get into our program, in order to fulfill these activities, rather than our bending a little bit we need to fit the person to that program. There is no shifting at all. That makes me very normal. It was something that hit me numbers of years ago now when 13-year old Terry came bouncing up the sidewalk in Sheffield where we were conducting a seminar, a paraspeaking with a number of youngsters present who had suffered the result of ingestion on the part of the mother of the drug Thalyomide. Terry was born with one massive disability as well as quite a few others. That massive disability comes out when I say he was coming up the sidewalk. No, he wasn't coming up the sidewalk - Terry was dancing up the sidewalk. He was doing cartwheels up the sidewalk. Terry had been born with no legs, and he came up that sidewalk bouncing and then bouncing into the house. It was truly a joy for the rest of us. I don't know what has happened to Terry since. I knew him as a youngster and I knew him when he was up toward ten and eleven, and again at age thirteen. He may well have artificial legs now, he probably does, but at that point he was quite willing to say that the doctors didn't need to make him "normal", and that he could get around faster the way that he was doing it. Even though it wasn't a normal progression at all, still he could get around faster, more adequately, and in a real sense more joyously than he would with artificial legs. Terry didn't feel he had to be made "normal". Maybe later he felt this more deeply, but at that point he did not.

In a city in Japan there is another one of those persons with exactly the same situation as Terry. He came into a meeting that we had only a year or so ago walking on his hands. In that restaurant he had it better than the rest of us where you sit at these low tables and the rest of us grunted and groaned to get down and he was right there. But he had walked in. He took off the heavy white gloves that he wore and then he joined in the seminar and discussion with the rest of us. He was 37 years old. He had walked on his hands for only the last 15 years. Prior to that his mother had carried him everywhere he went. He felt he had to seem normal and he couldn't progress in any other way. For various reasons artificial legs were somehow not immediately available to him. He could not get around from his home to the streetcar and get off where his law office was located. He could not do it on his hands. He had to do it "normally". How normal being carried by your mother is, of course, a question that all of us would raise. But, nonetheless, the sense of normality finally was overcome by him and he could say, "I can get around like the rest of you, only differently, and I'll do it." And for these past 15 years making him normal was no longer a problem in his life.

I am going to leave out some of these sins because we could think of a few more. Let us look at one or two more here. One is a sin that assumes that in our background the lessons that are there no longer apply for this present. Several nights ago I had a conversation with my father and my mother. Both are dead and, like all of us, we still remember the parent in us or the child in us and we have to talk with those significant others in our lives. I talked with my father and with my mother. "Mom, I continue to be grateful for that time when I was born (my disability is congenital). When I was born; no hands, no arms, and from what I heard later, the doctor said, scratching his head, "I've never heard of anything like this in my life, there is nothing like this in medical literature." There is now. "But Mom, for you to be able to respond to the doctor and say that somehow it will be all right and you affirmed that, and you affirmed it only a few days later when you were walking in the neighborhood carrying me in a little bundle and a neighbor acquaintance came to you and saw that I was there and said, blurting out the words, "Oh, Mrs. Wilke, I heard the church bells toll the death of an infant yesterday and I was hoping the bells were for your poor little crippled baby." And Mom, you said, "No, life is better."

I conversed with Dad as well. "Dad, I am grateful to you. Not too long ago I was swimming in the sea of Japan and it reminded me of the time when I was five years old and you taught me in a very special way how to swim. Remember Dad, you put together that four-foot length of board. On each end of it you secured an empty one-gallon syrup bottle that provided the flotation and then you said, 'O. K. Now you can push yourself out into the creek and carry on.' And I did. For five minutes I paddled around, it was wonderful. Then I put that thing to one side and I went off without it using my lungs instead for those empty syrup bottles. I went under and I came up sputtering and I tried again and I came up sputtering the third time and the fourth time I dog paddled all the way across the creek. I am grateful for that five minutes of thought, concern, trust, apropos, all of it you took for me which I used for five minutes and it was then a reality for me all the rest of my life. And Dad, also you taught me how to handle a gun and at the same time you also put deep within us your own strong and very negative feelings about hunting and trapping." Target shooting was really a good thing for us to do. We would go out and he would walk in front of me carrying a rifle at age twelve. That is trust. The sin of not carrying through our daily work, these lessons from the past, these lessons from the immediate present can be made a part of that.

One almost last sin, the sin of assuming no abilities or gifts on the part of these your potential persons with handicaps in your programs, potentially in your programs. Each of you who has had personal experience in life with a relative or a close friend have understood this for yourself. There is this sin which is very real. These gifts, these abilities, these strengths are there.

Let me just be personal again. This morning I am dressing over on the mainland and I did my usual thing. I follow something that I call the use of the third eye. The third eye is the eye of imagination, the eye of a higher stance of another perspective and that third eye in this case means that since for me putting on a coat and then buttoning it is enormously difficult, by looking at it with the third eye we find an alternative way of putting on this coat. This is a plain, ordinary, normal type of coat which looks like most everybody else's. This morning what I did was to reach into the closet, take down the coat and toss it on the bed face up. I buttoned it using all ten toes and then put the coat over face down and ducked into it the way you would duck into a pullover sweater. I sort of get down and do a little shimmy until it comes down over my shoulders and hips. This is the third eye approach and the sin of not using this third eye approach is one of the gifts that persons with handicaps can provide for us; alternative ways of fulfilling programs, alternative ways of doing things, finding a door that is not the main door or when there is no other door present, using a window. You use other alternatives and means of fulfilling particular programs.

The last sin I want to mention is the sin, is my sin of dumping on your shoulders all of these difficulties of persons whose very presence here means that you are committed to this and that obviously you already are fulfilling the involvement of persons with disabilities in your programs. So, dropping this last one as my sin and not yours, there are here at least six and the others that you can think of in your own work. Here is where we find some kind of perhaps illogical return for what we are about. And here are the places where we find something for ourselves in fulfillment of programs.

I want to end with a story that I shared with two or three of you before. I was coming back from a conference in Geneva and on the Atlantic trip. Of course, I spent time reading, etc. Obviously I read the same way you do, but I hold the magazine a little bit differently than you do so here I am sitting down in the seat and holding the magazine something like this in front of me. This watch here on my ankle was in plain view and the stewardess was zipping down the aisle and was taken aback seeing that watch there on my ankle and she said, "You are wearing your watch on your ankle!" I said, "Latest style, right out of New York." Then she smiled and went her way and came back five minutes later saying, "Sir, I am terribly sorry. I didn't mean to embarrass you. I didn't notice you were handicapped. I just saw the watch on your ankle." Of course she had not embarrassed me. All of us who have disabilities that seem to be obvious have long since learned how to respond to other's responses to us. But it got me to thinking about that watch. A simple old Timex, that's all it is. How do you get an anklewatch from a wristwatch? You add four links to the band and, brothers, sisters, this is what we are about. We are stretching our horizons. We are making that band way out. We are reaching out in our lives. This is what this conference is about and each time we think of an extra link here or there on our wrists or on our watch, that link talks about the involvement of persons, that link recognizes that our embarrassments are present. I ask you to add these different links to your watch band so your horizons may be broadened, that that band may be stretched out all the way and our programs will reflect that outreach and that stretching.

GREETINGS

Special Education

by

Joy McGehee
University of Hawaii

I want to extend my own welcome and tell you how excited I am to be here and be a part of this. I am in the Department of Special Education at the University of Hawaii so I am quite involved with the movement going on in Education right now to include students with disabilities in the mainstream of educational life and all of you are probably familiar with Law 4132 which came into being in 1978 and assures that all children will have the right to be educated with their peers. I spend most of my time deeply involved in this activity and I am very excited to be involved in an activity that works at including people with various kinds of disabilities in all aspects of society, not just in schools, but in recreation programs and social activities.

I really appreciate the opportunity to be here and introduce these people to you who are involved in it already. I want to make one little plug before I introduce everybody. There is, at this point in your life and in my life, segregation and discrimination that still exists and I want you to be aware of that. I know in the department where I work at the University of Hawaii, we are inaccessible to people who are not ambulatory or who have to come to the University of Hawaii in wheelchairs. They can't get up to the Special Education Department because we are in temporary units where you have to climb a number of steps to reach them. In fact most of the College of Education is inaccessible to handicapped people.

I am also going to alert you to the fact that we, in education, are concerned right now. We indicated a commitment on the part of the administration to people with disabilities and we would like to see that commitment continue in terms of money, in dollars. So I approach you, a little bit scared about what may be occurring in the next few years and hope that all of you will keep that in mind and continue to support our interest to integrate society.

UNITED STATES

by

Sharon Blintliff
Director, Handicapped Services Training Program
Honolulu, Hawaii

I am not going to talk as much about what I think we are doing as what I see ahead for this country. I wasn't around at the time of the agricultural revolution in this country, but I have to imagine that the disabled community was very well integrated and mainstreamed at that time. It is very obvious to all of us because we now are ready with the aftermath. At the tail end of the industrial revolution we found that we planned that whole scene without the disabilities community. Thus the architectural, the societal, the attitudinal barriers still are with us.

I think that we are making the first beginning steps into the next space age. I don't think that there are any of us who can, with our blurred eyes, imagine the societal changes that are in store for us. I think we are beginning to sense some of the deep societal upheavals. A very creative restriction of this society. I think we have all experienced or are beginning to experience what some have called the streak of meanness of the economics right around the corner. Someone said there is a streak of meanness coming in this country such as you have never seen before. There has been a gradual tearing apart of the families, terrorizing of aspects of our political system. I am beginning to doubt our judicial system the last couple of days, a shattering of many of our values.

Where will we see the disabled person? Where will we respond? How will we respond so the disabilities community is very much an integral part of our ways of this society? We hear about all the tales of disintegrating; whether it is nuclear or communal or traditional or nontraditional or however you choose to describe it. Now they are going down the tubes. I don't believe that. They are struggling to survivie. Our families are struggling to survive. That is still the place to be nurtured and if we don't support families, if we don't look to those programs and those policies which are supporting families, then I don't think it looks like a very bright future. I see many efforts being made. I would only draw an example to all of you which is so obvious and so clear. I just have to remind myself of that all the time because it doesn't make sense, never has, never will. Therefore, we probably ought to do something about changing it. We are willing to spend $30,000 to institutionalize someone, we are willing to perhaps spend $8,000 to have someone else care for them and absolutely zero to the natural family. This is where they really belong. They will probably get the most loving care there and yet, we are unwilling to support families to do that. I think we really need to rally to make those kinds of significant changes.

My wanting list is so long that no one else would have an opportunity to talk. We better go on and spend time looking at those things which really could change. The problem is that change is so hard. It really isn't if we all band together. If we really make up our minds to do something, we really can do it and families are where it can happen. But we have to support the parents however they come; one of each or two of each or six of each. We have really got to support families.

United States

There is no reason for us to continue to know the secondary and tertiary handicapping effects of certain disabilities and ignore that which could be done to prevent those handicapping effects of certain disabilities. We have talent, we have resources, we just have to make the commitment to see that we use them. We have a bright future. I am convinced of that and much of what I think we will learn as we move into the space age is that the kind of stick-to-it-tiveness, the kind of third-eye perspective that the disabilities community has brought is that which will help much of our coming age over the hump. I think that we are going to hopefully benefit from those that we see as disabled if we will allow ourselves to do that.

Its like Down's Syndrome children. Their impairment was so much more retarded than they were for how many years? Finally we were able to admit it. This confounds the medical profession. My medical students tell me that there is a squirrely professor down there because the first thing I say to the freshmen medical students is that we all are going to say together, "I don't know" three times. I want them to learn how to say, "I don't know" because one of these days they are going to have to say that.

We have a great deal to learn from the disabled community. We open our eyes and our ears and our hearts and give ourselves permission to do that. I think the greatest advances that we are going to make will be made with their assistance and I really hope that at least these United States and our brothers extended to the North, South, East and West will remind us from time to time because they are so far out, so far away from us. You can stand back and take a good look and then you scratch your heads and say, "How come those people in the United States don't see that,it's right under their noses." I think the disabilities community has been right here all the time. They have so much to offer and there are so many lessons to learn. I hope that is what we will do because we are really going to need them.

We are really going to need that perspective, but how do we extend the fewer dollars and how do we mobilize resources that don't have dollar signs. How do we give funds to families and say, "Go buy what you think you need." Let the money follow the need. We have never tried that, we have been too afraid. Bureaucracy is like that, but I feel there are many exciting things around the corner and I am excited about being a part of it.

PACIFIC ISLANDS

by

Michael Caldwell
College of Education, University of Guam

In a way I represent the Pacific Islands. At this point it is rather difficult to say which specific island, so I will assume we mean Micronesia which is between Hawaii and Guam. I think the sins Dr. Wilke spoke of may well describe the situation between so-called developed countries and developing areas or underdeveloped areas or lesser developed areas or whatever term might be for people or peoples who are not yet industrialized. As he was going through, I wondered how this related to so-called mechanized societies and the underdeveloped societies. There are many parallels. I think the western world societies are probably guilty of many of those things in relation to the developing areas. I was trying to think of how it applies, at least to the Americanized Pacific possessions. I think there are some pretty extreme situations.

Early in the 1960's I was involved in extending, or supposedly extending, social welfare programs of the U. S. Department of Education, Health and Welfare to Guam. One of them was the O.A.A. (Old Age Assistance Program). I remember this very, very clearly. When our program came to Guam there was much publicity as to how old people were going to be assisted. In Guam, and most of the Pacific up to that time, old people or senior citizens were automatically part of the family. They had duties. They assisted in child rearing and many of the things we are letting agencies do now. The concept was brought that somehow Grandma was supposed to have a pension of some sort from the government, which was called Old Age Assistance, but it was not too clear what this was. Guam's standards at that time were quite low in terms of dollars. The point was that the people involved had to have seniority to get the maximum amount of money and they had to live in separate households. This was because utility bills and things like that could be paid. This concept has grown in the last fifteen years now so that none of the young people feel that they have to have Grandma at home any more. She has to have a separate house, and the whole benefit of taking care of children and being involved with the family is more or less being lost. Grandma lives in an apartment or senior citizens housing complex which we have now instead of being a part of an extended family system where the old people, the senior citizens, were part of a young person's family and an ongoing part of the whole family system. I think skills that were needed in parenting were passed down through the generations.

Now we have moved all the way to the maximum point where we have isolated our senior citizens in small ghettos and we have supposedly made them independent. I think there is a great danger of that in many programs. They come from industrial societies and we try to make them a part of the developing nations. I am not saying that disabled individuals who live in developing nations do not need services, but I think we need to design and work with services to build on the strengths that are already there. I think we have to be very careful to recognize what those strengths are. This is particularly true of the Pacific and in Asia.

I have an opportunity to speak to you again tonight and I will be a little more detailed then. Another example, I think, that is quite good is the USDA food program. About a year and a half ago I had the occasion to go to the outer islands truck district and I went along and I noticed all these cheeses and butters and what-not carried in the hold of the ship. They were all taken ashore on the island and the magistrate issued them to the needy families. What was very fascinating was that as the ship returned back to the district center, many of those foods came back with it on the deck of the ship because the outer island families didn't particularly need the food and they were concerned about the people living in urban and district centers where their relatives were. So the food came out of the government consignment and went back to family members at the district center to feed their families. The government officials all knew this was the case, but somehow the system was organized to do it and it had to go on. I think in providing services and developing services in areas like this for disabled persons we have to keep these things in mind.

I was also reminded by various speakers of a Shakespearean quote which I think says, "It was the best of times and it was the worst of times". I cannot remember the play, but I think it is really what we are facing now. It is the best of times, but it also is the worst of times. If we are not careful, we could build a society like that of "Great New World". I think we are at a turning point in some ways and we have to look carefully.

If I have spoken negatively, I would like to speak now of at least one example of a positive transfer. This happened about a year ago. We had an individual who was a paraplegic from another island. He came to Guam to attend the University. Of course the University was building ramps and things that they hadn't done before. What I thought was most interesting - this individual had been paralyzed and wheelchair bound in the small Island of Coastgar for some 10-12 years. The family believed he wasn't supposed to do anything; he was supposed to stay home. He could not swim or go out or do anything like that. An occupational therapist happened to come to Guam and said, "Why doesn't he go swimming, why doesn't he get in the water?" Nobody knew. So he literally was taken one day and taught how to swim in the ocean. It was rather ironic because for twelve years he lived right on the beach and had been told by his family he couldn't do anything like that, so he never did. He did have to come to the western world to benefit from occupational therapy; in fact to learn how to swim.

There are going to be positive benefits and I think what we are going to have to do is to sort the good and the bad and try to know which is which and try to selectively develop programs in the areas like Micronesia and the Pacific.

INTERNATIONAL

By

John Nesbitt
Professor, University of Iowa

On the table out front there is an envelope that looks like this and inside it you will find a poster that Special Recreation was authorized by the U.S. President's Committee on Employment for the Handicapped to issue as a commemorative for International Year of Disabled Persons as a point of information. This is probably the first recreation graphic that has ever been issued in the United States in recreation for people who are disabled. This was issued in 1951 and we have re-issued it in 1981 as a 1981 International Year commemorative. Also in that envelope you will find a credo of Special Recreation, Inc. which is based in many respects on statements by the United Nations and the United Nations Federation of Human Rights and declarations relative to deaf/blind. A number of professional statements have been made as well as consumer statements that have been published on recreation for people who are disabled. You will find that in their credo of Recreation for the Disabled.

One general comment that I would like to make is that you and I, all of us here together, are in this situation together. The ideas that will lead to new strategies, that will lead to solutions to problems in the mainstreaming of people who are disabled are in your heads right at the present time. I wish us all great success in this conference in pulling those ideas and putting them together in a way that will result in a solution to problems with which you and I, all of us here, are mutually acquainted.

Based on my own ten years experience working with the professional staff at Rehabilitation International and with World Leisure and Recreation Association, I think it is valid to say that we are now in an era where there have been enormous advances in rehabilitation of people who are disabled. Those of you who have been very involved are aware of the different stages that we have gone through, the advances that have been made in the medical aspects of rehabilitation, the social aspects of rehabilitation. Over the last 50-60 years there have been tremendous gains in vocational rehabilitation. In the last 25 years we have seen tremendous gains in Special Education and in the last 15-20 years we have also seen tremendous progress in the area of recreation for people who are disabled. We are now at a point in time where in medical science the professions have yielded tremendous progress in rehabilitation for the disabled.

We are now moving into a new era of rehabilitation, a very important era of rehabilitation. The professionals and some of the delivery systems have taken this idea of capability and integration of people who are disabled, people who are functionally successful medically, socially, educationally, vocationally and recreationally about as far as they can. The big job is in integration in the community into the normalization within the community and family patterns. It is in the mainstreaming of people into the community. The dimensions of this mainstreaming that we have to be concerned about is the community participation in all activities. Full participation in education, full participation in employment. Both physical and mental health, mainstreaming in physical and mental health. Nutrition, recreation, mainstreaming into all aspects of recreation. Shelters and housing. Social protection. I think you may be aware of several thousand people who are, at least in terms of social protection, very vulnerable to crime, so this is another dimension of mainstreaming and social security. There are many important dimensions of this mainstreaming that we have to study together and work out solutions to the problems that confront us.

I want to reiterate some of the ideas that Reverend Wilke passed on to us that deal with attitudes. I think that those of us who are greatly involved or slightly involved take too much for granted about this problem of attitudes and what an effect that has on the life style and mainstreaming of people who are handicapped. My own interpretation follows a number of the researchers and writers relative to the integration and attitudes of people such as Gothen and McGregor and Barrett and Jordan, etc. Some of the attitudes in society have a profound effect on the potential for integration, potential for mainstreaming, the societal attitude that anyone who is different is less desirable. The negative characteristics create the negative attitudes and override the public's unconscious attitudes towards the disabled person which is negative.

We are not delivering fair shakes when we start working for people who are disabled and their mainstreaming potentials. We start at a very serious and profound disadvantage because, in the main, I believe the public has many attitudes toward the disabled. That means we have to overcome that just to get to the middle point, just to neutralize the negative attitudes they have and then work on creating positive attitudes. Some very critically important facilitator attitudes - none of the disabled people decide who may join; at school, at work, at recreation. Many professionals and middle class people perceive low competence among people who are disabled. Now some of these negative attitudes and the way they affect the person who is disabled, the adjustment of the sheltered person, are underlined by negative attitudes and the sheltered person's adjustment is dependent upon the attitudes of others. If a person is surrounded by negative attitudes, those attitudes will be assumed and result in a negative life style. On the positive side, some of the things that are open to us that will facilitate integration of mainstreaming. Enjoyable voluntary contact with stable persons increases favorable attitudes. Enjoyable voluntary contact with disabled persons increases favorable attitudes. High frequency of contact with disabled persons increases positive attitudes. Closer contact with disabled persons increases acceptance. I think that all of us have to take home with us the fact that there is a job for everyone in creating positive attitudes toward disabled persons.

Talking a little bit about the international sphere. One of the evenings we will be working on a special program on international activities where we will be discussing some workers reports on recreation for the disabled from Manila, the International Congress on Health, Physical Education and Recreation as well as the World Federation about Health and then a number of program materials that we have developed and recreation for the disabled will be presented Wednesday evening.

International

I do want to mention that Rehabilitation International, the organization that Professor Caldwell represents, has been very active in stimulating this International Year of Disabled Persons and is now making an activity called the Rehabilitation Decade in which we will be continuing these promotions and information activities during the 1980's. The International Council for Health, Physical Education and Recreation recently had its World Congress in Manila, the Phillipines and at that time there were specific programs on physical education and recreation for the disabled. The World Federation for Mental Health recently had its world congress in Manila and they conducted a special seminar there on attitudes of the disabled, and there is a very good likelihood that they are going to continue their activities. Internationally, it has been very gratifying to observe both the Boy Scouts and the Girl Scouts as well as the YM and YWCAs over the last 20-25 years who have been very active in international activities. Once again it is a great pleasure to be here. I would reinforce the idea that the solutions are in your head and that we all have a job to do. Thank you.

WELCOME

from George Yuen

representing
Governor George Ariyoshi

I am very happy to be here this evening on behalf of Governor Ariyoshi to extend to all of you his Aloha and greetings as you begin this very, very Hawaiian MAY Congress, sometimes referred to as Project MAY.

I think all of you know the goal of Project MAY, which is the forwarding of relationships or sense of sharing between the United States and all the other countries in the world, especially the countries in the Pacific Basin. Some of this sharing is concerned with the providing of opportunities for the disabled, the handicapped and those who are impaired.

I think this is a very, very special part of our international observation of the International Year of Disabled Persons. Many of you know that Hawaii has been playing a very important role in this international celebration. I think we all realize that a great deal of progress has been made, but in spite of this, there is still a continuing need for public awareness of the needs and contributions of the disabled. I urge all of you in Hawaii and the entire Pacific Basin to join in this great effort to contribute to more normalizing and productive lives among our disabled.

I know many people here in this room are responsible for the planning of this meeting and this very important conference, but I would like to commend just one person, Grace Reynolds, who is the Project MAY Director, and her staff and many volunteers who spent so much time to plan for this meeting. I know many fine and inspiring ideas will emerge from this meeting, and I wish all of you much success and Aloha. Thank you.

SPARK M. MATSUNAGA
HAWAII

WASHINGTON OFFICE:
[illegible] Dirksen Building
Washington, D.C. 20510

HONOLULU OFFICE:
[illegible] Prince Kuhio Building
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United States Senate
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CHIEF DEPUTY
DEMOCRATIC WHIP

MEMBER:

COMMITTEE ON ENERGY AND
NATURAL RESOURCES

COMMITTEE ON FINANCE

COMMITTEE ON
VETERANS' AFFAIRS

September 29, 1981

VIA TELECOPIER

Mr. William S. Suzuki
Coordinator for Project MAY
Congress in Hawaii
Camp Harold R. Erdman
Y.M.C.A. of Honolulu
401 Atkinson Drive
Honolulu, Hawaii 96814

MESSAGE FROM U. S. SENATOR SPARK MATSUNAGA

Kindly extend my warmest aloha and best wishes to all attendants at the consortium of private agencies' Congress today to commemorate the International Year of Disabled Persons -- the 1981 "Project May" -- Mainstreaming Activities for Youth.

As a former school teacher and father of five children, I recognize the vital importance of identifying the significant concerns of our youth and the need to reaffirm our commitment toward improving the quality of life not only for the young, but also the mentally and physically disabled in our community. Your Congress will no doubt provide an excellent opportunity for the exchange of ideas and information as well as a forum to discuss the specific role of private youth agencies in fulfilling their commitment to the young citizens of America.

Your cordial invitation to the principal speaker at the opening session of the consortium is greatly appreciated; I regret very much that Congressional duties in Washington prevent my joining you in person. Nevertheless, my thoughts are with you for a most rewarding and productive congress.

Me ke aloha pumehana.

Sincerely,

Spark Matsunaga

Spark Matsunaga
U. S. Senator

WELCOME

From Robert K. Masuda
representing
Mayor Eileen Anderson

The Mayor is sorry that she is not able to be here this evening. She is presently in San Diego attending a conference and working on some projects related to the City and County of Honolulu. She sends her regrets, but she also sends her Aloha and best wishes for a productive and fruitful conference for all the local people who are here and especially a fond Aloha to all of you who are visiting from other states, for our many friends from Asia and the Pacific Islands and from the big island of America.

On behalf of Mayor Anderson, we welcome you to the City of Honolulu and we hope that the fellowship that we share here will be as rewarding as the kind of intellectual and professional stimulations that you get here from your colleagues. I would like to ask Dr. Anna Marie Brault, the Director of Health for the City and County of Honolulu, and her husband, Dr. Roger Brault, to stand and as a team, we would like to welcome you to the City of Honolulu.

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CULTURAL SIMILARITIES

by

Michael Caldwell
College of Education, University of Education

First off, I am pleased to be here in relation to my professional orientation, as well as from a personal viewpoint. In relation to my role as Secretary-Treasurer for the Asia-Pacific Regional Committee of Rehabilitation International, it is my pleasure to bring you greetings from Rehabilitation International President, Dr. Harry Fang of Hong Kong, and Rehabilitation International Vice-President for Asia and the Pacific, Professor Charlotte Floro of the Republic of the Philippines. As an American professional special educator, who for the past sixteen years has worked in the Western Pacific and Southeast Asia, I appreciate this opportunity to share with you some information which may serve to highlight the possiblity that while cultural and linguistic differences abound among Pacific peoples, these differences may not be quite as important as the similarities which exist among the same people by virtue of commonalities of economic, physical environments, general social structures, etc. Such factors, in turn, result in disabling conditions. Furthermore, there is an indication that many of these commonalities may well be shared with some populations in North and South America, as well as Europe.

The United Nations General Assembly proclaimed 1981 "International Year of Disabled Persons" and cited the following objectives for the proclaimed year:

(1) To help disabled persons in their physical and psychological adjustment to society;

(2) To promote all national and international efforts to provide disabled persons with proper assistance, training, care and guidance, to make available to them opportunities for suitable work and to ensure their full integration in society;

(3) To encourage study and research projects designed to facilitate the practical participation of disabled persons in daily life, for example, by improving their access to public buildings and transportation systems;

(4) To educate and inform the public of the rights of disabled persons to participate in and contribute to various aspects of economic, social, and political life; and

(5) To promote effective measures for the prevention of disability and for the rehabilitation of disabled persons.

In doing this, the United Nations gave recognition to the needs of the world's some 400 million (WHO estimate) disabled people.

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Cultural Similarities

Of this 400 million, also according to a World Health Organization estimate, on any one day, 60 million people in the world could be helped to a better life through the provision of rehabilitation. Such rehabilitation would result in improvement of their functional capacity via educational and vocational measures and, even more importantly, in better acceptance in the community. All of this is aiming at better integration of the disabled into the mainstream of our societies.

The establishment by the United Nations of 1981 as the "International Year of Disabled Persons" is clearly in keeping with its earlier actions--namely, the Declaration on the Rights of Disabled Persons (General Assembly Resolution 3447-XXX); the Declaration on the Rights of Mentally Retarded Persons (General Assembly Resolution 2856-XXVI); and Resolution 1921 (LVIII) of the U.N. Economic and Social Council on the prevention of disability and the rehabilitation of disabled persons. These expressed actions by the major world level international body seem to clearly indicate that disability--its prevention and remediation--is, in effect, an international concern which transcends cultural, ethnic, and linguistic differences.

On a broader, humanitarian basis, we have learned from the works of Desmond Morris (the Naked Ape and the Human Zoo) and others that all humans sequence time and energy for basic biological, physiological, and psychological needs. Within the finite limits of available time, energy and related resources, increased attention to one area of human development cannot be accomplished without sacrificing needed time and energy for another; thus, from a resource point of view, time and the resources utilized by a family, a city, or a country to simply maintain a disabled individual in a non-productive/non-contributing manner is, in effect, detrimental to the family and the society, as well as to the disabled individual. This is born out particularly by the concluding statement in a recent publication of Rehabilitation International ("The Economics of Disability: International Perspectives," 1981) from which I quote, "The results of available research studies do not appear to demonstrate any conflict between the humanitarian basis for rehabilitation service provision, and the basic principles of socio-economic planning. Disability will create a cost to society regardless of whether or not rehabilitation services exist. In fact, it appears that the more a society recognizes these costs, and the more it attempts to ameliorate them through the provision of adequate disability prevention and rehabilitation services, the greater is the overall economic return that may be expected. It is thus apparent that we have been too cautious in evaluating the full impact of disability and rehabilitation service provision in economic terms, and that a greater understanding of these forces will serve to strengthen governmental motivation to implement the most essential humanitarian principles."

A common strand across cultures, and among nations, particularly in the Pacific, in relation to disabled people is the need to gain a clearer understanding of the potential role sound, on-going rehabilitation and disability prevention practices can play in overall economic development. Related to this, "participation" has become one of the most dynamic concepts being employed in efforts to understand and find solutions to the problems of disability. Thought about it has emerged as a logical development from the examinations of normalization, integration, mainstreaming, equal rights, and independent living that have dominated the discourse of the past decade. The universality of this interest was demonstrated when the United Nations General Assembly adopted "Full Participation and Equality" as the theme for the International Year of Disabled Persons (1981). Its spirit was reflected in the proposal of the Assembly's advisory committee, representing 23 nations at every stage of development, that the name of IYDP be the International Year of Disabled Persons-- not the Year for them.

Now, this Congress with its goal: "To share between the United States of America and other countries, the principles and concepts of providing opportunities for the impaired, disabled and handicapped to participate in programs and services provided by community and human service groups" is a significant extension of these same efforts.

Earlier, I indicated that I would present information which would relate to cross-cultural-national commonalities in relation to disabled persons within the Asia-Pacific region.

In doing so, I am relying to a great extent on my own observations, supplanted by technical reports and materials which have become available primarily through the World Health Organization, UNICEF, U.N. Economic and Social Committee for Asia and the Pacific (of which Guam is now an associate member), and Rehabilitation International. In relation to Rehabilitation International, I have been privileged to serve, for the past two years, as Secretary-Treasurer for the Rehabilitation International Regional Committee for Asia and the Pacific. This opportunity has helped to further my understanding of the needs of the regions' disabled persons.

The total population of the countries within the Asia-Pacific region was estimated to be more than 2,289 million in 1978 -- 70% of this population then lived in rural areas (1978 demographic estimates for Asian and Pacific countries, Population Division, ESCAP). While totally accurate data on the disabled among this population is not available, a report, "Childhood Disability: Its Prevention and Rehabilitation" prepared by Rehabilitation International for UNICEF (E/ICEF/L.1410) indicates that one child out of every 10 is born with or acquires a physical, mental, or sensory impairment. The information collected during the field surveys made for the report indicated that the percentage in developing countries is likely, if anything, to be higher. Most studies have shown that, in general, a tenth of the world's population is disabled in one form or another and to varying degrees. Even in developed countries, the relative percentages of disabled population are reported to be higher than this.

However, allowance must be made for differing definitions of disability. For example, in Australia, the commonwealth Bureau of Census and Statistics undertook, in 1968, a survey of the disabled in five of Australia's six states. It was based on personal interviews with a 1% sample of the population. The information obtained from the survey was not supported by medical evidence, nor was any information obtained on the degree of disability suffered. The survey indicated that approximately 1,909,500 persons, or 23% of the civilian population, suffered from one or more chronic illnesses, injuries, or impairments, and 40% of these reported that the condition limited their activities in some way (Comparative Study on Legislation, Organization and Administration of Rehabilitation Services for the Disabled, ST/ESA/28).

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Surveys and reports also indicate that the greatest number of disabled persons live in developing countries. Taking all these together, a figure of 320 million disabled persons in the Asia-Pacific region would, if anything be an underestimate. Or, in other words, 60% - 70% of the world's disabled persons reside within this region.

A study conducted by Rehabilitation International noted some facts which are particularly relevant to this region. Among these, is the fact that while it is in the developing countries in which most disabled persons live, little or nothing is being done to prevent either the continued occurrence of impairment or to ameliorate its damaging consequences.

Further study of the subject was undertaken by the United Nations in cooperation with the International Labor Organization and the World Health Organization, utilizing information collected up to 1971. Although the study is selective, dated, and not all countries from the Asia-Pacific region were covered, some basic trends become clear from the reported findings. Except for one or two countries/territories in the Asia-Pacific region, most of the others had little in the way of organized services for prevention or rehabilitation, or supportive legislation: in some cases where no legislation exists or in those where it does exist, it has not yet been implemented. Information indicates that the number of trained staff is totally adequate.

Two interdependent reasons for the inadequacy of services in Asia-Pacific developing countries seem to stand out. One reason is the general ignorance at all levels of the conditions of the disabled. The second reason, which stems from the first, is the very modest amount of money allocated to develop such services and support. To some extent, this is understandable. In some countries where living standards are very low and where there are a host of problems to be faced--among which are the scarcity of food and essential commodities, lack of irrigation and power, high prices, unemployment, etc., the allocation of resources for disability prevention and rehabilitation tends to be modest. The argument usually given by planners and administrators is that nothing more can be done -- a view which is conditioned by their having to make difficult choices between different areas of the development spectrum. These choices are, however, made on the basis of the knowledge of a problem. It is, for instance, the knowledge of the long-term benefits of irrigation that prompts large investments in that sector. The minute amounts earmarked in most developing countries for disability prevention and rehabilitation are, unfortunately, based on lack of a true understanding of the reasons why programs for disability prevention and rehabilitation are essential in a development program. Ignorance, and an almost total absence of information, was found during the study conducted by Rehabilitation International to be not only true in the case of illiterate villagers, but also in those of community leaders, professional people, government officials, and international planners and administrators.

The urgent need to encourage more effective action in this field in relation to general development programs stems from a basic socio-economic fact: no country, particularly a developing country, can progress as rapidly as it would wish if more than a TENTH of its population are denied the opportunity to contribute to the productive activities in all sectors of the economy, but rather are obliged to live off the earnings of others; and no society, developed or developing, can expect to grow into a healthy, integrated society where every individual participates in and enriches the life of that society if, in fact, a tenth of its members are isolated and denied access to the social and economic activities of the majority.

As indicated earlier, an estimated 70% of the population of countries within the Asia-Pacific region live in rural areas. It would be reasonably accurate to assume that a similar proportion of the disabled population would also be found in rural areas; the percentage of disabled persons in rural areas may well be higher given the fact that such facilities as do exist for prevention and rehabilitation are found mainly in urban centers. Of the rest, it can be assumed that, by far, the larger number of disabled persons would be found in the urban slums that surround a large number of Asia-Pacific cities. There is a strong indication that segments of the Asia-Pacific disabled population have little or no access to preventive or rehabilitative facilities. In rural areas, communications are difficult--in some places non-existent--and there are no effective means of taking facilities to such places on a regular basis. Even a simple network of primary health care facilities does not yet cover all rural settlements in the countries of the region. Besides, field surveys in some countries have shown that when such programs (primary health services) or other developmental inputs are made available, the least benefited, and the last, are the disabled: this also seems to be another consequence of the ignorance, superstition, and prejudice that permeate nearly all levels of society in much of the region.

Intervention strategies have necessarily, therefore, to be designed principally for the disabled living in rural areas or in areas where services are difficult to deliver--such as urban slums.

One of the distinguishing features of the Asia-Pacific region is the extremely wide disparity in all levels of development between different countries: in 1970, for example, the per capita gross national product ranged from (Australia) $US 2,820 to (Bhutan) $US 70 (International Bank for Reconstruction and Development, World Bank Atlas: Population, Per Capita Product and Growth Rates, Washington, D.C., 1972). While no quantified data on social development are readily available, it can reasonably be assumed that usually (though not always) a high level of economic development would also mean highly organized social development systems--among them the delivery of comprehensive services to the disabled.

More recent observational data would indicate that Japan, Hong Kong, Australia, New Zealand, Taiwan, and possibly several of the American territories within the region have, in the last 10 years, widened the gap between themselves and many of the lesser developed countries/areas within the region. The extent to which the newly acquired expertise and capability of these areas will be able to effectively assist in the lesser developed countries/areas within the region move ahead has yet to be clearly demonstrated.

Appropriate intervention and rehabilitation programs are suggested in the recommendations of the Advisory Committee on the International Year of Disabled Persons. These relate to measures to be taken at the national level. Although they cover a wide range of potential actions, they none-the-less emphasize two general major subject areas: (1) preventive and rehabilitative measures, and (2) the integration of the disabled into the mainstream of society. These two general concepts, in fact, can serve as general headings under which most of the other recommendations will fit.

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However, in the Asia-Pacific region--where the vast majority of the disabled have no access to any services at all and where ignorance about the disabled and their potential as students, trainees and productive workers is almost total--major importance needs to be given to at least three somewhat lesser, specific actions. These are:

(1) Measures to bring about changes of attitude at all levels--possibly through mass media campaigns. This is among the first of the Advisory Committee's specific recommendations.

(2) Assessment of the incidence of disablement (most Asia-Pacific countries lack this basic information).

(3) Establishment of appropriate governmental machinery for the implementation and coordination of all policies and action on the various aspects of prevention and rehabilitation.

A major need of disabled people within the Asia-Pacific region, and possibly the entire world, is positive, integrative action. In this sense, legislation is considered a comprehensive term consisting of the following elements:

(1) The integration of the child in the education system and the modification of the educational content of school curricula to include vocational preparation of the disabled child in the context of his or her personal abilities and potential. A large number of handicapped children are not sufficiently helped because of the lack of adequate pre-school facilities as a component of their education, provision for the inclusion of disabled children, either within the regular program which would be the most desirable--or possibly a separate program--would make their later education considerably more effective. Necessarily a pre-requisite for both pre-school and school education is provision for training of the personnel involved, and training courses which are designed to insure acceptable standards of competence are maintained for the personnel so trained.

(2) The integration of the disabled adult in the economic infrastructure where, hopefully, through utilization of regular training institutions and centers of specialized learning, the working qualities of the disabled adult can be developed. It is desirable that such training or specialized education be given in so far as possible in existing institutions for the able-bodied. However, it should be recognized that in some cases, specialized institutions may be necessary. Vocational rehabilitation centers will play a crucial role in this field; in some Asia-Pacific countries, however, at present, such existing centers tend to function more or less in isolation from regular educational and training centers and often do not lead to the placement of the disabled person in employment. It is important that strong coordination be encouraged in this area. However, a need for the provision of sheltered employment exists for those disabled persons who will not be able to work in open situations.

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It would seem that it is particularly important that a systematic identification of occupations be made by teams or groups which would include experts from the field of medical rehabilitation and vocational rehabilitation, selected employers, and, hopefully, the disabled persons themselves. Such an identification process will lead to real jobs for disabled persons.

Effective promotional campaigns and demonstration programs to focus attention on the potential of the disabled person for productive work would need to be organized.

(3) Of particular importance in relation to this Congress is a need within the region to:

(a) Access the disabled to public places, sports and recreational activities, and educational and working environments; it would be of particular relevance to consider changes in building codes or regulations which would make this possible without increasing expenditures substantially.

(b) Shift in emphasis from institutional care to home care. While it is clear that in many Asia-Pacific countries the family has been, and still is, performing the main, and often only "rehabilitation" a disabled person received, the economic fragility of most families in rural areas is a constraint, and the support that can be provided by itinerant rehabilitation workers or teams of workers who would impart their skills and make available environmentally appropriate aids and special equipment needs, should be seriously considered. In some cases, institutional care may be unavoidable for a number of reasons. But, from all points of view, effective provision of basic support facilities and, above all, counseling and guidance to the family should prove to be the best course of action. A very recent example exists in the simple project within Micronesia which simply modifies an essentially good home training program (Portage Project) to linguistically and environmentally fit the real-life conditions of children and families being served.

(c) Inquiries into existing legislation which causes discriminatory practices or actions directed toward the disabled child as well as the adult needs to be made and followed by actions for their removal. It has been found that in many Asia-Pacific countries the structure and nature of socio-economic activity creates discriminatory conditions--often not consciously, but rather owing largely to demands and necessities conceived as being those of the able-bodied. For example, certain standards of physical fitness may be laid down for a particular job which, in reality, could be performed by disabled persons with or without aids. Yet a disabled person who is otherwise qualified would be rejected only on the grounds that he or she does not possess the basic standards of physical fitness. The Comparative Study referred to earlier bears out the difficulties faced by the disabled in this field; for example (p. 175), Pakistan reports that "it is difficult to find employment for the disabled in general"; Burma reports "a certain reluctance on the part of employers to hire disabled persons." In the Philippines, "the usual wage rate paid to the disabled is 75% of the normal amount." In Australia, disabled workers may be legally paid less than the "award rate" subject to "the approval of an industrial inspector or magistrate in the form of what is termed a 'slow workers' permit."

Perhaps the greatest handicap that a disabled person in the Asia-Pacific region has to face is, oftentimes, a considerable or complete lack of knowledge and information among the able-bodied concerning the disabled. This is related to the disabled individuals' ability to learn and benefit from training and to engage in economically useful occupations. Indeed, this ignorance very often develops into prejudices and fears, and, in a number of countries, into superstitions which highlight the disability and even rob the person affected by it of the attributes of a human being.

In the words of Norman Acton, the Secretary-General of Rehabilitation International, at a symposium on "Disability and the Developing World" help in Washington, D.C. in September 1979 (e/ICEF/Misc. 318): "there is an abysmal lack of accurate information about these things; and an equally appalling wealth of misinformation, prejudice, supersition and fear. This is a major factor in the family's inadequate reaction to the problem when it arises; it is a fundamental reason for the community's ostracizing individuals and families that are affected with disability; it exists in the institutions that might be helping, but aren't--the health center, the school, the religious groupings; it permeates all echelons of government from the village chief to the ministers of health, education, welfare, labour, community development, planning and whoever else may exist; and it is endemic in the representatives of international and other organizations who are advising on the procedures and priorities of development, and administering international assistance. This absence of information and understanding, and the manner in which it reinforces the traditional distorted concepts of disability which flourish throughout the world, does much to conceal the real magnitude of the problem and to confuse everyone's thinking about the solution."

The enormity of this ignorance is so pervasive and has become so ingrained in society that it includes the disabled themselves. Born into or living within societies permeated by ignorance, prejudice, fear and superstition, a disabled person comes to look on himself as an outcast, as someone incapable of useful work, a person who must depend on charity and remain cut off from a normal social life to the end of his days. This is particularly true of those who are disabled owing to a "stigmatized" disease such as leprosy, epilepsy, etc.

The nature of action in this area will, therefore, necessarily have to be intensive and sustained over a long period of time; programs will have to make use of all the communication media available in each country/territory. It has been found that mass media campaigns by themselves are often not adequate; the use of individual contacts, group discussions, demonstrations, and other techniques will be of benefit. The "motivators" or those who organize campaigns at the base level in rural areas or urban slums should preferably belong to and live within the community: experience has shown that motivation and community education is best done by such persons. Target groups would have to be chosen: families, teachers, employers in industry, etc. for specially designed communication programs.

At this point, it is possible that some would say that it is simply a matter of assisting the countries/territories of the Asia-Pacific to reprogram their available resources into a system which will deal with problems facing their disabled populations. Unfortunately, this is not really the case. An example from the World Health Organization Program and Policy for Disability Prevention and Rehabilitation (p. 24) helps highlight this point: "It was recently recommended that rehabilitation services be set up in the capital city of a developing country. The recommendation closely followed the conventional design of an institution in Europe or North America. It was then recommended that services be extended through the provision of a similar institution in the second largest city, then in the third, etc..... When this plan was scrutinized, it appeared that if the country's entire health budget were utilized solely for rehabilitation services, it would take sixty years to develop the necessary manpower, or about 200 years to provide the present needy population with the desired amount of care." This anecdote, while describing a situation in Africa, could well fit many of the conditions existing within countries/territories of the Asia-Pacific region. While it helps to highlight the similarities among Asia-Pacific developing areas, it in turn helps to differentiate much of the Asia-Pacific region from North America and Europe. It becomes clear that new and more Asia-Pacific regionally-oriented delivery systems must be developed and implemented. Activity has been initiated to meet the need. Time and space will not permit an elaboration at this time, however, I look forward to informal sharing of ideas and concepts with many of you during the remainder of this conference.

In closing, I would like to share with you a "Prayer of the Afflicted" which was inscribed on the wall of a work area in a Philippines grassroots-level rehabilitation project which I visited last month.

> We do not ask that you return our sight
> but we do ask that you open the eyes of our society
> to discover the true values of justice and peace.
>
> We do not ask that you give us back our legs
> but we do ask that our brothers walk united toward you.
>
> We do not ask that you restore our hands
> but we do ask that you teach us all
> there is more joy in giving than in receiving
> that brotherhood is sharing everything as you have done with us.
>
> We do not ask that you raise us from our beds
> but we do ask for the strength to teach the hearts
> of those who have given up, who do not believe in the light.
>
> Amen.

COORDINATION OF RESOURCES AND FUNDING

by

Janet Pomeroy
Founder and Director, Recreation Center for the Handicapped, Inc.

I hope to cover some of the techniques we can use to coordinate our resources. I also want to talk about funding resources and coordination of agencies and also discuss trends and plans for responding to them. This is a new era in which I think it is very exciting and I am really very thrilled about some of the things that are developing internationally today. Some of the public attitudes, I think now about government spending and increased compatability and management by objectives and all of these factors, have been changing our image and also some of the things that we have to learn. I believe these are very challenging and exciting times and I think it is a tremendous time in which we live. In my own work I have had to learn to wear many hats because recreation is a diversified field and fulfilling needs of all aspects of human services. Recently I heard someone say that the technical skills they need in this day and age in our field are education including education, advocacy, psychology, sociology, political science, journalism, public relations, fund raising, secretarial, law, computer science, business, and I've added one other; the ability to walk on water.

It will be 30 years next year of providing community based recreation programs for the disabled population. We found ourselves in all of these technical areas that I mentioned and think it is because we have been very responsive to the needs of the severely disabled persons in the community as they arose and we found ourselves to be evolving, we literally evolved around the needs of the community. If you don't serve the needs of the community, there is no point even being in business.

For example, right now we are serving over 1600 severely disabled children and adults, ranging from infants to the elderly in their hundreds, but when we started getting referrals I originally started with physically handicapped who were not severely disabled or mentally retarded. When we began to get referrals from severely disabled people in the community as well as the handicapped this created a need for social workers. I never envisioned having social workers on the staff. Then as we moved into other areas there was the need to serve breakfast, lunch and dinner which meant we had to have a chef and cooking staff. The enrollment of severely disabled persons greatly increased the transportation need. We now have 40 buses. Schedules eventually had to be put on computers.

When we saw a need to serve homebound persons we organized an outreach program and then that meant that we had to learn new ways of training staff involving deatn and dying.

Most of our people are institutionalized. We closed many of our state institutions in California mostly for disabled persons. When this was first started only mildly handicapped and disabled were involved. Now we are getting those whom you would only see in a state institution and we are serving them. This meant we had to have technical teams, consulting teams in different areas including rehab and psychiatric social workers and psychiatrists and so on.

Wnen we responded to the need for a day care program there were 200 children waiting to go into state institutions - we started a day care program for this group. Incidentally none of them had to be institutionalized because eventually

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we took all of them. This also created another need for such persons as pediatricians and then consultants from the community who could help us with IPPs and assure individual program plans and a linkage with other community agencies.

What I am saying is that when we let the center evolve, we just had to get involved with everybody in the community in order to stay afloat. Over the years we have served 10,000 people and many of them have moved out into community programs. This meant the need to design and construct new facilities costing millions of dollars. We are in state approved facilities which are all paid for. This was a chain reaction. Every time we responded we created a chain reaction which demanded another support service. But we realized that meeting the needs of morbid disabled infants to the institutionalized, mentally ill and mentally retarded and often elderly, meant going that extra mile. It meant that we had to get the people in the community involved with us to help us with our training and with all the support services. It really meant that in order to do this type of program we were getting involved with almost everybody in the community. I found that there were many, many sources in the community available to both public and private agencies. I believe this is true in every community. I think that they exist and the same resouces we found you will find in all other communities.

It is a full time job to locate and coordinate these resources. It is very, very challenging and it is very, very inspirational to be working with so many persons. I have thought about this since I have been here. We still have to develop community awareness. There are four areas that I would like to speak a little bit about. I think that education, advocacy and demonstration of our program and politics is one that I haven't heard much about but I want to talk about it because it has been very important to our industry.

One of the things that I have seen is that education is involved in all of these areas. We have a situation down in California where the state has put recreation on the bottom of the list in terms of priorities for funding. I had talked with legislators who really don't know anything about recreation. I think sometimes we still have to interpret recreation for disabled persons. People don't understand recreation at all, let alone recreation for disabled persons. I was talking to one legislator and he acted as though he thought it was, and I guess he did think it was, a kind of a token activity that one should supply for the disabled persons, especially for the mentally retarded, just to keep them from walking the streets.

We have much to do in the way of education. I think one of the things that I feel about community recreation and community based programs is that at some point the municipal recreation and park people are going to have to consider serving the severely disabled, multi-handicapped disabled persons in the least restrictive environment or we are going to have to have more public and private agencies organized to do this because even though we have enlarged out into the community, and are gradually moving some of them out, our department still is only serving those who can get to their programs through their own means, by buses or their own transportation. We still have much to do in advocacy. It is safe to say that we have found that parents and consumers have been more of advocates for themselves. Of course they need help but once they get into it they really do like it and I have seen this happen. For the past five years parents and consumers have been helping me as advocates against the city. The city was trying to build a waste water sewage plant about 300 feet in front of our brand new facility and we have been battling them for all these five years. We are winning the battle. With God's help we have won it because the last I heard was that President Reagan cut off all their funds.

One of the ways that we have educated the community is that over a period of 29 years we have constantly had our participants in the community. I can remember when people were insulted and made all kinds of remarks where now, after 29 years, they are gradually beginning to accept them, and I guess San Francisco has to be one of the worst cities in the world for that. There is a change over all of these years and it is about time.

There are two things that we think have helped; it serves two purposes. One is a scale of development and increased self confidence of disabled individuals themselves and the other is the increased acceptance of the community because, as they see them and see what they can do, they are capable of going in restaurants and theatres, and doing the same things anyone else is doing. I guess they begin to allay some of the public's fears, and stereotypes are reduced. Also we have found that if we get people to visit our center and see what the participants can do and see them in programs we can sell our program. When the public sees them enjoy themselves and participate in an activity, they really want to help. That is how we get much of our help. We feel if we can get the community educated we can sell them.

Over the years we have managed to get a very good contact with the news media. We have good, ongoing publicity. We have a logo which is used on all the TV stations year around on some very popular programs and ball games and that sort of thing. People see this logo and thus we are very well known which we should be after 29 years in the community.

The other thing that I notice - that television has been doing a very fine documentary, showing the severely disabled. When I first started they wouldn't even think of photographing anyone except a very nice looking Easter Seal type poster. A person who was a beautiful child might be shown as handicapped or have a disability, but they wouldn't take some multi-handicapped person. Just recently,however,one of our local TV stations selected one of our most severely disabled young men to show his whole life style. It showed him going to work and it showed phases of his personal life and then our own program, and it was very well done.

Another way that we are educating and advocating constantly, we started this 29 years ago, is that we have had an annual Thanksgiving dinner. It is held just before Thanksgiving and we have all these donors and all the city officials come out, including the Mayor and all the Board Supervisors and all the people who can help us with our funding in different ways Now, in our new facilities, people become angry if they are not invited. It is the place to be and they come to be seen. We are very happy about that because we do have a great deal of support from the city now but it has taken many years.

Now I will discuss what I call the "bread game". This is politics. I think when I started the center in 1952 I avoided politics. Of course, I was so naive when I heard about even the foreign politics but I saw a great deal of it.

There is no city, I think, that can be more political than San Francisco. I started with a small grant and the city had given me the use of an old building and it was furnished with heat and gas and lights by the City Recreation and Park Department. I felt that eventually they would take the program into their department after I got it started. I found they had no intentions of doing that and for twelve years I went through all the proper channels and didn't want to get involved in politics. I approached the Recreation Department three different times and asked them for funding and every time I was turned down. The last time I made a study that lasted four years and at the end of four years they said they couldn't do any more than they were doing which meant the loan of the building and heat, gas and lights. It took me twelve years to become angry.

I was very fortunate to meet a State Senator who told me that politics might change the department's minds. It was a very simple procedure of using the census context to introduce the media to a series of articles showing the center as a struggling agency providing a needed service for severely disabled persons with private funds, all this time with private funds, and it was rightly the responsibility of the Recreation Department. They brought out the fact that at that time the Recreation Department had been budgeted some 15 million dollars and were not giving the center any help. The efforts of the media, of course, gained city-wide attention and especially focused on the city hall. Eventually the department called and said get these newspaper people off our backs and we will help you. I found though that they never wanted to include it in their program. They said there was just too much red tape and they didn't want that, but they would contract with us. I found, that was my first lesson, you can beat city hall if you have political know-how.

Now we have a very good public-private partnership relationship with the Recreation and Park Department that has lasted for 17 years. From that time on I have learned that especially if an agency has any kind of local funding from municipal parks, or the city or the state or federal, it's absolutely necessary to become politically involved. This has to be a continuing process because financial resources change and the politics change. It is necessary for an agency to keep a constant watch on protecting every area of resources at all levels of government. For example, we found that there was a tremendous need for us to get involved in the government state-wide plan for development of the disabled. About 15 years ago we participated in the setting up of priorities. We had to go to all of those meetings. Many of us got together in recreation and talked about the need for recreation for the developmentally disabled. We never would have received any money because they had funding problems, but we kept verbalizing the need and, as a result, today recreation day activity programs still have the top priority in the regional state plan for the developmentally disabled population in the State of California.

This was definitely achieved through education, advocacy, demonstration and politics. We do a great deal of lobbying at the state level. Several years ago California reached its ceiling on allocation of federal funds and for the last six years they had to augment Title 20 monies for services to be maintained with the cost of living increase. In 1977 Governor Brown decided not to go with these funds which meant that we were going to lose our Title 20 money so our staff and about 60 participants sat in the Governor's office overnight for three nights. (Some of our people loved it, they just loved being there though it was very difficult for them to sleep on sofas and that sort of thing). They were there as advocates and after the three nights the augmentation was given by the State and since that time they have asked us please not to bring those severely handicapped and disabled people to the Governor's office.

In 1979 our agency got together with all the other agencies associated with disabled persons to form a coalition. That was a very good thing to do because we were able to support one another and attend many legislative meetings. We took busloads of participants to hearings and it is pretty hard for a Senator to make a decision against a disabled person who is sitting in the front row of a large group of advocates and parents and some of their constituents. We found that it is necessary to know the legislators. You have to meet with the legislative aides. You have to know something about the legislation, checking on bills and laws and deadlines. You have to write letters. There are just so many things that you have to do. I learned from the "bread game" that you don't put all your eggs in one basket. The Center has five contracts now and they proved to be very successful for direct funding. I'd like to describe them briefly.

The first one is the one with the Recreation and Park Department. Our allocation with them now is close to $400,000 a year. That money is used as matching funds for federal funds. For every dollar we get from them we can match it with $3.00. With that we have a contract with the Department of Social Services for Title 20 money which covers SSI (Social Security Supplemental Income) for children and adults who are disabled. We have to attend their meetings. We have to go to City Hall. We have to contact the Mayor, finance team, board of supervisors and all of those things. We do the same thing with our Department of Social Services contract. We still have to be there and be verbal. We have to take some of our participants to be there as advocates.

The third contract is with the State Department of Education, Office of Child Development and that is for preschool and day care and serves severely disabled on a year around basis. We are one of six agencies in the State of California that has this contract with the Office of Child Development. This was done definitely, through politics. We never would have received it any other way and all six of us stay together. Last year we got together because each year we think that the money is going to be cut off because there are so few of us. Each year it looks as though we will either be cut off or cut back, so last year we got together and shared expenses toward a child consultant who could be up there all the time and could lobby for us. She tells us when to appear, for what committees at the State Capitol, what materials to have, and what to say. This is a valuable person to have. Our State Senator from San Francisco has also helped us a great deal, but I had to go up just before I came here. It looks as though now we are going to have this as a permanent financing on a permanent financing basis because we also have the Speaker of the House supporting us.

We also have a contract with the regional center. I don't know if any of you have these in your state, but it is a fiscal agent to handle State Developmental Disabilities Funds and they have a State Council and the state determines the rates. This we have to lobby constantly. We are lobbying now to bring our ratio up because we are not there to quote costs. We have the state food program, too, that covers the cost of food for children up to 18 years of age. It is a very complex program with many forms and paper work, but it saves us at least $5,000 a year on food.

There are many politics also that are not as much actually involved in the private funding. I want to talk some about private funding because I think that is where many of us are going to have to go more and more, public-private partnership approach. I know that there are many proposed changes in federal, state and local funding that probably will have an impact on recreation programs for disabled persons, but we are not afraid because we have learned now to go on by faith and not by sight. We believe that if God closes one door, He is going to open another one. If Reagan closes some doors, I know we are going to find some other doors. We still raise 27% of our budget through private bonds. We get most of it through foundations and corporations. Of course, this means we have to learn something about grantsmanship and constitution research and how to approach the private sector. Someone said yesterday that we have to have a degree in granstmanship. I learned it the hard way, but I have never had a course in grantsmanship, but I have been fairly successful in finding grants. I don't want anyone to think that we have to have definite degrees or courses or something in this because the person who is involved with programming is the best person to write a grant application anyway.

In approaching a foundation, one of the things we have found is that there are millions and millions and millions of dollars to be given out by these foundations and corporations. The University of California just recently affirmed this stating that more than 2 million dollars an hour is given to non-profit organizations by foundations, corporations, and government agencies. I believe that - I believe that very much. One of the Executive Directors of a foundation, the biggest one in San Francisco said that that is absolutely true. They have a great deal of money; it is just a matter of approaching, encroaching and selling them on recreation. We did that years ago and some of them have been supporting us for years. Some of the foundations now require that two or more agencies have to work together. They are getting the idea, too, of very much cooperation among agencies for they want to make sure that there is no overlapping. They also changed their priorities. Until recently, one foundation, which used to give heavily to education and recreation, recently changed its priorities to minority groups, death and dying, alcoholism, gay rights, planned parenthood and Gray Panthers.

A great deal of our funding comes from service clubs - fraternal men's and women's organizations who helped us from the beginning and who are still helping us, such as the Rotary, Kiwanis and all these clubs. A directory of all of these is available from your local Chamber of Commerce. Get on their list of speakers. That is how we started with that. We have many small groups who raise funds for us. They use our center as a place to raise funds, using our large multi-purpose room for any activities such as potluck suppers and carnivals and square dancing. We have a square dancing group that raises about $5,000 a year for us. We have crab feeds. The parents also are very much in the fund raising. We are going to have a casino night very soon. We have an annual benefit horse show that is sponsored by the Sheriff's posse in San Francisco. They have raised up to $25,000 a year for us. We were very successful in having all of our buses donated because people love to see their name on a bus. Foundations and individuals who donate buses have their names on the buses. We have one person who has given us three buses. He likes to see his name.

It is also possible to become named in a person's will. One way is to contact the local attorneys, write them letters or visit them, and give them your brochures and tell them about your program. We found that there are many people who, when they pass away, have no idea what to do with their money and so they leave it to some attorney to distribute or they leave it to a community foundation. That is why we have so much money in San Francisco. Trust departments of banks should be contacted. I have one person from this group on my board. Such persons are invaluable because they already have contacts and know how to go after trusts.

In the last ten years we have become involved with corporations. I read the other day where 16 billion companies in the United States donated 2 billion dollars to charity in 1980. Most corporations have a foundation. If they don't have a foundation, they have a committee that deals with contributions. They can be approached and if you know anyone in a corporation that is a very good way to go. I've seen some very interesting things happen that I think are trends in corporations. Moreand more, I feel, they are becoming aware of their role in helping the community and they are developing what they call CIT teams, Community Involvement Teams. These teams are made up of employees who visit local agencies to see how they can help and they will select an agency and then they decide on a suitable fund raising project. Whatever they chance to raise, the company matches it.

For example, Levi Strauss has these teams everywhere. They came to our center and they decided, they committed themselves to raise $30,000 to replace the floor in the multi-purpose room. What they did was to coordinate their interest with some other group, in this case they coordinated it with the Hyatt Regency in San Francisco, and they agreed to contribute all of their teen dancing funds and all the money that came out of wishing wells for a certain period of time. I think it is in Kansas City where they had to stop theirs for awhile (teen dancing) but they have gone back to it now. They get the publicity for all these things, too. They had a kick-off for the whole thing where they had coins in the fountain. They called it "panning for gold". On the opening day they had TV cameras. So these agencies that you work with can help you in getting publicity. They had all their managing directors from Levi Strauss and, or course, they like publicity, too. It works in many ways. You get publicity for them and they help you.

Another example is Standard Oil. The Standard Stations put up $32,000 recently. They have the same kind of thing. They have a team, involve the team in the community to sponsor city-wide renaissance to benefit our center. They did this in cooperation with a local TV station and the TV station did all the news, the broadcasting, we had tremendous coverage. It took a whole year to organize this but this is going to be an annual fund raising event. We didn't raise as much as we wanted to raise or thought we could raise, but we are going to continue this. Standard Oil has agreed to do this. They used to have very few requests for funds. They now get hundreds a day so they are all becoming aware and they are assuming their responsibility. They know that they can write off much of this and they believe they have a responsibility to the community and many others are helping.

Another thing that we have been involved in and I am sure some of you have, too, is what I call "bargaining." I think we will have to learn to do our bargaining in a creative and unique way. We have been doing this for quite a number of years now. It is also tied into public relations. I would like to give you a few examples.

We write a little brief proposal, maybe a half a page about adopting a program for a one time type of idea. We make it like $25-50,000 a year and some of them have money for including mainstreaming after school, recreation programs for disabled children, day care for autistic children, programs for senior citizens, preschool programs for severely disabled children, day care for disabled children, homebound recreation for terminally ill school children. We did quite well. We have several corporations that like to give to a one time thing, such as field trips. We have had a group that went to a wilderness camping, a trip to Yosemite, Tahoe and canoeing and that sort of thing. Some corporations will give up to 20-50 thousand a year if you show them you are going to spend it for a number of trips. Then there can be requests for camperships and parent-child swim programs. We even promoted gasoline for our tanks. We have our own tanks now and we have one that needed 10,000 gallons. We had two donors give $5,000 each and fill it. Groups like to give to furnishing activity rooms or providing wheel chairs or swings or sandboxes or physical fitness apparatus, projectors, all kinds of equipment. Most of them do not like to give for staff salaries or office operation.

I would like to talk briefly about sharing and coordinating with other agencies. I call it a real partnership that I think is absolutely essential and, as I mentioned before, I think we are just about involved with every agency in the community. I certainly think it helps avoid duplication and sharing among ourselves. We have several natural forums where we can get together such as Adult Disabilities Council, that was established several years ago. We meet and share our experiences and information. It is the best way to learn to be able to work together. When I first started, agencies serving disabled people didn't speak to one another. Now agencies are supporting one another and sharing. I'd like to mention a few ways that we share. We share all our information and materials, nationally and internationally. We even share all of our proposals and annual reports and all of these things. We share our facilities for meetings, for forums, workshops, fund raising activities. The center also provides transportation for eleven other agencies. There are agencies that have workshops, day care, independent living centers and others for whom it would be difficult, very difficult, for them to try to buy buses for all of those things. It is much cheaper for them to purchase transportation and the cheapest transportation they can get would be to work it into our regular center. We drive for all these other agencies.

All the schools for disabled use our swimming pool to bathe in. They are not paying for it. We let them do it because there is no other place for them. We are also doing a lot of reverse mainstreaming which is continuous and especially with disabled children and their parents, non-disabled parents and their children and disabled children. We are teaching parents to teach their children to swim and we have some as young as 3 months old. The center is also used as a drop off center for children whose parents are not at home when they get out of school. They used to drop them off at Juvenile Hall and now they can come to the center and we take them home, wait until the parent gets home. We have 150 therapeutic swimmers from the general community who are referred by physicians for weekly warm water swimming. These are persons who have had strokes and arthritis and burns. It is amazing what this warm water is doing for them. We have a community gym program that was developed for abled and disabled children in the gymnasium. We have many young children from the community attending and they love the facilities because they are new.

We are also looking into satellite programming with other counties who do not want to start programming in their own department. We are showing them how we could help them, through our own staff, in starting programs in their community. They are very excited about it and they can make a contract from us the way the department does. Some of the agencies share with us. The YMCA - we use their facilities all the time, especially for resident camping. Community College Districts, I am sure some of you are using the adult educators. We have six. We use the Jewish Community Center and we have many different teams. We have one for community health services.

Janet Pomeroy

There are three agencies in San Francisco that are designed especially to help non-profit corporations and I hope you have these kind of agencies in your community. One is called Community Services Project which was set up by a foundation. They get people from all these corporations to teach courses such as management by objectives, public relations, budgeting, fund raising, grantsmanship bargaining. All of this is free from a non-profit corporation. It includes staff relationships, recruiting and training of volunteers. There is another agency called Management Center that does the same thing. The Junior League is involved.

I will discuss some of the trends we have seen and what we are planning to do about these trends. I got involved with what is typically called elderly. By the year 2010 there will be 40 million elderly people in the United States. The majority will not be institutionalized, only 5% are in nursing homes at any one time. This means that 95% would remain in a home within their own community. The Administration on the Aging has outlined the need for multi-purpose centers that provide a comprehensive program through a coordinated system of social services and efficient transportation, an outreach of information referrals, homemaker services and we are doing this for the elderly in our outreach program anyway. We are planning, in our twenty year plan, to construct a new facility and one would be a plan for a multi-purpose room for the elderly, particularly the frail.

We feel that we would like to develop some of our staff. We already have several of our staff who are in foreign countries. Some are traveling around the world. We have many college and university students who spend time at the center. We are going to construct conference training center dormitories and to have 150 people at one time. That's really looking into the future. I don't say that will happen, but we are working on it already. It would be an educational training center. We also want to develop and publish a wide variety of handbooks for implementing recreation programs.

In conclusion I would just like to say that I think serving those that are disabled in the neighborhood, particularly those that have been institutionalized for long periods of time involves many different areas that may or may not be useful. I think it is very exciting and it certainly can be done. I think we have to continue to educate and to advocate and to become politically involved and to develop community awareness and also have to find financial support if we are to package and market our programs. I think each community has to identify the needs of its special population and examine the resources. I do believe these exist in every community. The key is commitment to the recognition of their needs and the determination to provide services to meet those needs.

We began small. I think that is important to focus on quality programs, not on numbers, and I think it is only through quality programs that a disabled individual will be able to reach his potential and take his place in society, the mainstream of society. I just wanted to say that I really think these are very challenging times and we have to step out in faith. I think that when God calls us into this field, He will give us the resources and the wherewithal to continue to expand. I believe every community has resources.

I want to wish all of you the very best of luck and God bless you.

COORDINATION OF RESOURCES AND FUNDING

Response to Janet Pomeroy

by

Harold H. Wilke
Director, The Healing Community

I am going to give five responses to what Janet Pomeroy has said. The first is that in each case that she has mentioned, a caring community has been predicated at the base. Her concern about the Lord is a figure which I obviously would respond to very positively, but that concern was expressed in terms of a caring group involved and I want to mention at this point, please turn to a little document that you have in front of you called, Open Doors. It looks something like this and on the last page of that you will see a statement, "A caring community is involved." I feel strongly that the center of San Francisco is an illustration of the fact that the caring community is at the base of it.

My second concern is that you need program pegs, program pegs on which to work. Again, Janet, you mentioned in several cases where you picked up specific points and whether it was using some of your people to do sit-ins in the Governor's Mansion or wherever, you developed this program around particular areas on the calendar and in the program of the community. The program pegs, it seems to me, are of real importance. I do point out to you that the National Handicapped Awareness Week is being celebrated this year on October 12-18 and The Healing Community has added three days to the front of that and three days at the end. Two weekends are also involved in order that we can have something called "Access Sabbath Sunday." I ask you to use this as a program peg in your communities and your programming as a peg for hanging programs. There is a mention of this in a purple document that you have. It looks like this and it is available in New York from the Office of Mental Health Developmental Disabilities and it is free. If you do not have their address, write to my office and we can provide some for them - 44 Holland Avenue, Albany, New York.

A third comment is that in all of your work you should use, as Dr. Pomeroy put it, the involvement of persons. Not just that very pretty five-year-old blonde with calipers on one leg, but instead, persons with very real repugnance to some of us, disabilities as well. I ask you now to turn to page 11 in a little document you have called The Caring Congregation. There is a set of statements by Bob and Martha Persky which it seems to me are critically important. It seems to me that four or five of these were utilized by Janet in her program. One of those is to adopt a zero rejection policy as you work with persons with mental retardation. This is a critical factor in this report.

My fourth comment is that in what is being done - the long time that Janet was in that beat,run-down old building with the bad floor and everything else. Architecture is, of course, of importance, but you notice that all the way through she was speaking about the matter of attitude. We need to see again and again that the development of the attitude of the individual, the attitude of the person who is disabled and the attitude of persons who work with them is of critical importance. You have a document in your hand called, The Ramp

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Is Not Enough, and the printer should have put an exclamation on that because that is the way I wrote it originally. "The Ramp is Not Enough" and we need to be concerned as well with our attitudes. We need to be concerned even more with attitudes. We need to be concerned with the communication involvements. This is all a part of it.

My final response is found in part of that same document. The back of it is something called, "The Ten Commandments for Our Relationships with Persons With Disabilities." I might add here, parenthetically, that Moses wrote all of these commandments. To be quite honest, I wrote them on a mountain near a mountain top in May and I add also that Mrs. Moses rewrote Commandment No. 4. My wife said, "Harold, that is pretty stodgy and you had better change that one," so she did.

That first commandment had to do with the liberation which is involved for us when persons with disabilities are indeed liberated as we saw in Janet's film last night. The liberation, the freedom, the new sense of being a person really came through in that film and, of course, came through in what Janet said today. That commandment which says that "I am God, Your Creator. I have brought you out of bondage. Liberation is a sign of the life I give you." What you are doing in liberating persons in opening them up to the wholeness that is really theirs and the fullness and quality of life that is theirs by right, is doing something which is at the very basis of the universe. God has ordained it to be. That liberation you see is not just for this individual, however, it is for you as well.

Yesterday I said that I had talked with my father. Last night I talked with my mother who has been dead for ten years or more and my word to my mother went something like this. "Mom, I am grateful to you for that time that I knew about only by hearsay from a long time later, that time when I was on the floor in the house struggling as a very small child, to get into my shirt. Mom, I understand that you were standing there watching me and that your friend and neighbor was standing there beside me watching me and that the neighbor woman said to you, 'Why don't you help that child.' At which point, Mom, you were standing there with your arms at your sides held rigidly there with your jaw clamped tight because every instinct in you wanted to reach out and put that shirt on over my head for me, you said quietly and firmly, 'I am helping him'."

The freedom, the liberation which is involved for me, of course, was a liberation for my family as well and the freedom and liberation not so much for tactile, for actually working with our hands with individuals, but the new sense of freedom that comes out of the fact that we no longer have to be bound by attitudes toward them. That they are part of the parcel of this whole community, a new freedom comes to us as well.

SMALL GROUPS SUMMARY

By

William P. McCahill

Volunteer, Boy Scouts of America

You have all had a real information overload in the last two days and it isn't over yet. Many of the somewhat routine or almost innocuous pieces of paper that you have been given have real hidden gems among them, and this includes some of the material upstairs on the second floor of the taller of the two hotel buildings here, opposite the headquarters. Don't feel like you have had too much in too short a time because we hope you have a long lifetime in which to digest much of this material. If you haven't visited the little exhibit room, there are still some very wonderful gems. One of the things I found most helpful to me was something that was given me by a volunteer Girl Scout. It told about programs in Santa Clara. I wish she had brought a hundred copies along so you could all share it.

Sally Price led the discussion on physical impairment with 25 people on hand. The group agreed that the goal was to be as independent as possible. We are a very independent group and that came through almost all of the reports. Much could be accomplished in daily living skill programs for those with aqquired disabilities. Then there was some discussion of the contrast between rural and urban areas relative to equipment, such as wheelchairs, and the comment was made that the equipment was much cheaper down under than the air travel and also that in some places like China, Japan, and Taiwan, air travel was much more difficult as compared to some other western countries which were more used to people in wheelchairs moving about. A support system was recommended for those stroke victims or other major disability victims who find that the loss of their previous companions was as severe a blow as was the disability itself. Many people tended to be left behind by their former peers.

As in almost every other session, an emphasis was placed on the attitude barrier relative to the severely disabled. For some 30 years I used to go around the country for the President's Committee saying that we have broken the altitude barrier, but we are still working on the attitude barrier. Finally, in Sally Price's session, it was pointed out that some doctors don't level with their patients. They don't really tell them what their problem is. Some families are really a bigger problem than the disability that the person happens to acquire.

Next came a group discussion on mental impairment led by Carol Eblen and the gist of those discussions was summarized in three parts of basic specific information needs:

1. There was a need for direct service methods in mainstreaming.

2. Community organization methods in mainstreaming were essential.

3. Information on presently available and the working mainstreaming systems should be shared in a greater extent, such as those being used by the Boy Scouts, the Girl Scouts, the 4-H, Girls Clubs and some other youth serving groups. This is not to say that others are not doing it. These are the only ones that were mentioned.

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Then came the delightful session I was in with Colletta Whitcomb on sensory disabilities. Each of the three people with eye problems gave the background of their eye disabilities and the annoying and sometimes amusing incidents that came along with the onset of the disability including Linda's situation where she was a cradle-blind person and the process of growing up, as well as the friendly little gray dog she had with her when she was here. Each of the presenters was actively involved as volunteers in Y groups in Hawaii. Colletta Whitcomb said at the onset that she never made speeches, she only read them, and she read us a very fine twelve page speech she had written out and then she talked in a very delightful manner. She admits she was "legally blind" and told us that that was one of the five categories of blindness. She discussed her growing up and generally coping. In fact all three of them shared their coping situations despite some of the problems which agencies sometimes put in their way. She gives her husband most of the credit for her normalcy and acceptance of her by other people and her acceptance of other people. Linda and her seeing-eye dog classify her blindness as an "inconvenience" saying that the peak of her adjustment and the adjustment of other birth-blind children was getting to the blind person early and helping them very early in life. She said that everyone was different and this came through in all of the sessions. We are individuals - God doesn't make replicates. We are all separate and distinct and individual and agencies should and could be more flexible in dealing with their clients. Sometimes the agency's rules and regulations were such that it made it difficult to handle the personality of different kinds of people.

She also said something which I learned very early on in my career on the President's Committee working for fourteen years as a seeing-eye Marine for General Boss, that blind people can only be helped when that help is asked for. That certainly is something we can all remember if we don't know it now. It is best to let a blind person ask you for help rather than to grab their arm and help them and in the process push them into a door or a chair they can't see. Fred Zatinski, who was "diabetically blind", mainly later on in life, also has to depend upon dialysis three times a week. Agreed again, each person should be treated as an individual and not slotted as he said, a procedure which he found personally disagreeable and which he fought against when he tried to get some services as a newly blind adult. In his rebellion he mentioned that he and many other people who lose sight in adulthood were involved in anger and self-pity.

Thre has been a great deal of literature on this subject which points this out and this is quite normal in many sighted people who lose their sight in life. Unless people who have this happen to them are well prepared in advance, especially those who are diabetic and have been warned that this is coming, it is a much more traumatic experience judging from his own comments. John said that this diabetic situation is getting worse and worse and the thing to do is to catch them early and prepare them for the onset of darkness. That way they will have a firm mental attitude in coping with what they have left.

During this session I mentioned a seminar on Scouting for the Physically Handicapped in Washington on November 2-4. Although we can't pay your way, we want any of you who are interested in coming to know that it is in the Mayflower Hotel and is put on by the Boy Scout Committee. I'll be glad to waive your $50.00 registration fees, if you can get to Washington.

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Small Groups Summary

A question was brought up about what was being done for the deaf-blind and although this is a program that actually had to do with sensory disabilities, most of it was devoted to the blind. There was very little said about the deaf except I did mention that we had run the first national seminar on Scouting for the Hearing Impaired in Gallaudet in 1979 and plan another one next year. I mentioned that Gallaudet College was working with the deaf-blind, and several other people knew other places where deaf-blind people were being helped. Bob Smith, who was, after Helen Keller, the first college graduate to be deaf-blind, was at one President's Committee meeting. When he got the President's trophy from Vice-President Hubert Humphrey, he read Humphrey's remarks by putting his fingers on Humphrey's lips and then said out loud, in his rather mangled speech, exactly what Humphrey had said. It was a very moving experience. I also mentioned that we had given Helen Keller a distinguised service award, the first and only one that we ever gave that was in Braille. It was the first and only time we were on television. We have talked today to those among us who probably have the worst possible disabilities and the worst possible sensory disability. They may be hale and hearty in every way, but being deprived of two of your senses is certainly a major problem. There is a general consensus that the State School gets the patients when it is too late and this may be one of the problems that the State School has; that blindness is something that requires preparation when medical evidence indicates the onset. I mentioned this certainly with regard to Fred and it was mentioned that they were working on this early warning system and working toward a goal preparation.

There were also three small group sessions on Wednesday, one being really quite small on elderly disabled persons under Dorothy Devereaux and I was facilitator. Both of us gave a little background on how we got into this work with the handicapped. Dorothy said she was more concerned with quality than quantity and she didn't mind at all that there were many people down the hall that weren't as interested in the elderly as we were. She told of her Way Ministry Care Home and how the people there had the blessing of the spiritual emphasis upon their lives at least twice a week where Dorothy gives the elderly an opportunity to both heal and be healed, at least spiritually, if not physically. They are able to participate in a glow of the feeling of accomplishment in jointly sending their group power of holding hands and praying for others, both there and throughout the world. I pointed out that we did something like this in our Catholic Charismatic groups back in the mainland and also the great pleasure and privilege I have had of taking Communion to sick and shut-ins as an Extraordinary Minister of the Holy Eucharist of the Catholic Church for the last several year. For twenty of the people, it was the only visit for that week. It is really a wonderful thing when we can bring religion and spread some quality to the lives of people broken and bent.

To summarize a lively session, the Chair wrote six points on the board and then asked the questions, very pregnant questions I might say. The points were:

1. Why were there so few in our group? You can answer that yourselves.

2. What will happen when the institutional funds are cut, which certainly is the handiwriting on the wall? In fact it is more than handwriting, it is coming.

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3. There is a great need to strengthen the concept of the extended family in America. We talked a great deal about the extended family as we have talked in some of the other sessions. This is difficult when children start school at the age of two. It makes it very difficult to keep an extended family in place in many instances.

4. We must constantly stress the cost benefit thing when talking with legislators and people who make decisions about budgets, namely that it is much safer to keep the aged at home than to put them in institutions. It is a great deal cheaper and a pathetically small gain, in some cases, for the outoing money.

5. There is a great need for an overview of all community care facilities today.

6. Where are all the volunteers coming from? Is the supply exhausted in what we understand is a period where the present administration is expecting volunteers in the private sector to pick up more and more of the load? So is the supply of volunteers already overburdened?

The question Dorothy Devereaux asked was, "What are you going to do about all this when you get back home?" Now Mrs. Devereaux said that the grant should have been called "The role of youth and service to the elderly disabled." Several suggestions were made as to how the youth, handicapped or otherwise, could be involved in serving the disabled elderly. A new Boy Scout merit badge on handicapped awareness is one thing that was mentioned where youth could be involved with older persons with disabilities. Mrs. Devereaux displayed two publications or brochures with primary answers for people living here in Hawaii, but with the aid that is provided by other states or by other communities by the same or similar agencies. One was A Guide to Resources published by the Executive Office on Aging of the Governor's Office and the other is A Key to Resources Serving the Handicapped on Oahu published by the staff of the Commission on the Handicapped in July, the third revision, so they are keeping it current. I suggest that sufficient copies be brought here and made available to you today. It is well worth your taking one, particularly if you are from the Islands. I understand they are working on a similar project for some of the other islands.

Next came the Youth Agency Services under Dr. Nesbitt, which played for a standing room only group, aided by Andrea McLean, recorder. Andrea has several pages recorded which were digested by Dr. Nesbitt to the following six headlines:

1. There is a need for direct therapeutic service personnel to work directly with youth service agencies wishing to provide services for disabled persons. Their consultation and assistance on projects is very much necessary.

2. There is a need to more fully utilize existing resource material such as Boy Scouts, the YMCA Project Aquatics Mainstreaming, 4-H material, Special Recreation material which Dr. Nesbitt has here,

and others. Since there is a great under-utilization of all of the existing material, we still reinvent the wheel in too many instances. This takes time and money and is counter-productive. So the point was made that we should know more about what is available. We should use it and not try to do things that have already been done better.

3. The key to program development is as simple as making a commitment to provide service. Sounds like an echo of the San Francisco remarks by Janet Pomeroy. In other words, don't wait for the money, just get the program started and the money will come in most cases. It reminds me of the old story that "all things come to them who wait" and that is true provided "he worketh like hell while he waiteth".

4. There is a need for more direct involvement of disabled consumers in planning and in evaluation.

5. There is a need for increased dissemination of information on programs and models. We have almost been disseminated to death and John Nesbitt brought some material today that you can have if you didn't get here last night.

6. There are unused sources of available volunteers such as senior Boy Scouts and Girl Scouts, youth (high school and college) such as the Boy Scout alumni and the college fraternity of Alpha Phi Omega which is on many campuses across the land.

The third and last group yesterday was Therapeutic Recreation for Adults presented by Robert Masuda with Robert Dye of the YMCA as facilitator. They came up with four major points for your consideration:

1. Less than one percent of the Y's handicapped and disabled are engaged in a meaningful recreation program.

2. Despite the census system of locating handicapped and disabled, we still have no clear idea of either their needs or their demands.

3. Before mainstreaming can begin to happen, training and involvement of staff and professionals and the general public is essential. Mainstreaming also begins with the family.

4. Limited local available transportation is the major expense in implementing mainstreaming as is the availability of facilities at the precise time that they are desired for the handicapped applicants.

5. Two major necessities for an effective program are commitment by agencies with energy and funds to proceed and collaboration in joining forces with other agencies already providing services and facilities. Going it alone will no longer be tolerated in our day due to funding and shrinking budgets.

Small Groups Summary

Those of you who were not able to profit by the very illuminating program with Dr. John Nesbitt and his wife, Dr. Delores Nesbitt, last night can share that by picking up and taking home with you some of the material that Dr. Nesbitt has here. Their presentation hit the following points:

1. Disabled population needing recreational opportunities is possibly the largest aggregate disabled population in the United States. You think about that for a minute. I think what they were saying is that everybody who is disabled needs recreation.

2. Relative to community or special recreation for the disabled based on a three year $40 million United States Office of Education project, there are available some twenty-five hundred pages of public demand material already available with no cost or any copyrights. You can get copies of anything you want at the Special Recreational Educational Resource Information Center. That is ERIC. That is what ERIC is if you haven't met the young fellow. That young fellow is alive and well in quite a few libraries. In fact there are 700 around our great United States. This includes also Twenty-Mile Programs from as many cities. It includes 50 sources of information and material. It includes monographs on recreation. There is information on federal funding, rural recreation for the disabled and a whole host of other things. If you haven't met ERIC, get to know him and you will find him very helpful.

3. International Special Recreation for the Disabled is really moving along. It has taken a long time. I worked with Dr. Nesbitt back in the 50's and 60's so I know how long this has taken. For one thing, the International Seminar on Special Recreation was conducted in Manila this July, a terrific program which Dr. Nesbitt shared with some of us here today.

   Back in Winnipeg where some of us were working not too many months ago, last year in July, the Rehabilitation International World Commission of Leisure and Recreation was formed and a gentleman from Japan was made chairman of getting the Pacific Basin a head start on leadership in the field of recreation and the whole international community of rehabilitation.

4. There is an extensive recognition in the United Nations in all of their documents. Some of them are quite old in terms of the United Nations. Many of them are relatively new and you have several of them in the materials that Grace has made available to you in your kits. These go on. They shouldn't be left in packages. They should be used as we have used them here in referring to them from time to time when we are speaking.

THE INTERNATIONAL SCENE

A ROUND-UP

By

John C. Sevier
Volunteer, Boy Scouts of America

The Hawaii MAY Congress presentations by the presenters can be divided into three parts: the Mainland, Hawaii and the International Sectors. It is this latter portion that is the concern of this report to the plenary session. Key professional personnel of the vendors of services to the enabled and disabled populations served as the presenters of their programs and were from Canada; Hawaii; Japan, including Osaka, Hiroshima and Tokyo; Taiwan, or the Republic of China; Malaysia; and Australia.

Included among the presenters were:

Andrea McLean	YMCA	Edmonton, Canada
Tsuneyoshi Tsuneto	YMCA	Tokyo, Japan
Taiji Hajime	YMCA	Hiroshima, Japan
Yoshio Ono	YMCA	Osaka, Japan
Chung Chian	YMCA	Taipei, Taiwan
Chang Weng Chiu	YMCA	Kuala Lumpur, Malaysia
Diane Morgan	YMCA	Sydney, Australia

They came from five nations and seven cities.

In his opening charge to the Congress, Reverend Wilkie referred to the commonalities shared by the enabled and the disabled populations rather than to their differences. This same reference can be made to the programs presented by the different vendor agencies in the different areas represented in this Congress.

Irrespective of the national origin, the agencies all provide life survival learning situations for the disabled population they serve. Money management, shopping, consumerism attitudes, transportation usage, time awareness for the mentally, physically and sensorially disabled populations. For the enabled population, sign language classes are provided to extend the communication with the hearing impaired populations. Pre-vocational training is also a part of the total programming available to the disabled populations. In Taiwan the blind are prepared for employment as masseurs or masseuses, a familiar employment opportunity in the republic of China.

Life support programs are also made available such as physical training and development for the mentally retarded and autistic, a very necessary activity. Recreational programs are also offered to enrich the lives of the disabled.

Although professionally directed, the use of volunteers is an attribute of the vendors' services, requiring continual recruitment and training. With growing frequency, all of the agencies are turning to high schools, community colleges and universities for their volunteers.

The International Scene

The financing of all these services for the enabled and disabled populations likewise has a commonality. Services for the disabled expenses are shared, in part, by the disabled, avoiding the implication that the service is a charity. Part is absorbed by the agency and part is obtained from the public and private sectors through direct solicitation. For the most part, all of the vendors indicated growing problems in procuring funds.

A noteworthy comment on commonality is that IYDP has provided an impetus, the growth of services, where most of the programs began in the decade of the '70's. Some agencies' services to the disabled antedated those beginning in the '70's.

It is almost a universality that only a small portion of their potential market is served by the vendors, all expressing the need to increase their communications with the disabled to increase the numbers served.

It must be noted that not all subpopulations were being served. To quote one of the presenters, "When it comes to serving the mentally retarded persons, we ourselves are retarded. We have much to learn about serving this population."

Aloha!

POSITION STATEMENT

by

Grace D. Reynolds, Project MAY Director

First I want to thank each and every one of you for responding the way you did to the position statement. Our advisory committee and some of our resource groups have met and digested two or three page documents over the last year and have come down to a simple statement that we hope you here and the Pacific Nations and those on the Eastern Seaboard, as well as across mainland USA, will use. But, as Wayne said, if you will take it back, we hope that this will be a way to open the door and that you will go to your executives or if you are the executive, you will implement it with your staff. We would like to see that we have some way to go on into the future and we have many ideas of how we would like to do this. But if you can take your statement and say a part of the Project MAY Congress in Honolulu, the group felt that this was something that we should do.

I am sure you will have different ways of working with it. You are in a different country, you are in a different situation. If we can all go forward helping to spearhead active development, programs, open doors for board members, help train staff, then the three years that we have been working on MAY as well as the other six years that we spent doing some other kinds of projects, will be well spent because we have a future and the future is really in your hands.

John C. Sevier, Volunteer, Boy Scouts of America

I have another response. I think it is somewhat akin to the agency from the international area that spoke yesterday. I hope that both MAY (Mainstreaming Activities for Youth) and IYDP (The International Year of Disabled Persons) somehow or other find the means to go beyond the end of this year. The last two years of its life have sown some good seed. Much of it has fallen on battle ground and it is beginning to grow. The early MAY activities in New York, at Philmont's Scout Ranch, led to additional meetings in Denver by other than MAY personnel, where I had the privilege of taking part in addition to the activities of the MAY personnel. These expansions on the original seeds are going to be won, but need to be nurtured and their growth has to be encouraged. I ask that consideration be made that MAY will go forward continuing its activities beyond Year III, next year, and I certainly hope the spirit, if not the fact, of IYDP will continue on. It has given a strong impetus to the agencies serving the handicapped population. Let's hope it continues to grow.

Paul Kuromoto, Nuuana Branch YMCA, Hawaii

Adopting a position statement is a very important thing and I would hope that we all take this back to our own agencies and not let it gather dust on the shelf. But for those of you that have Boards of Directors, share it with your boards and make it become a position statement for your board and for your agency. For those who do not have boards, certainly bring it into your staff planning, goals and objectives and implementation. Position statements can really direct us and I hope that we will use it. I am happy that we adopted it here this morning.

THE CHALLENGE

by

Gerald L. Coffee
Captain, U. S. Navy

Introduction

Captain Coffee was shot down near the Vietnam coast while flying a routine reconaissance naval mission and was taken prisoner. He was held in Panamoya prison for seven years and nine days.

His captors were hostile, his treatment was humiliating and his cell was small with a concrete slab for a bed. He was subjected to frequent interrogation and torture.

Summary

Mr. Coffee's speech dealt with the changes in attitude which he experienced during his captivity and the lessons which he learned - lessons which are valuable for all individuals facing stressful situations.

His prayers changed radically from, "God, if you would just give me those last five minutes to fly over again, I would surely fly somewhere else" to "Please, God, get me back to my loved ones, my family, my country. I don't know how long I can take this." Finally a turning point was reached with the determination to make the best of the situation and become stronger because of it. The prayers then became, "O.K., God, if this is the way it is going to be for however long, then please, Lord, help me to make this time count for something good and positive. In my personal dark ages, help me to turn it around to be my personal renaissance. God, help me to go home a better and stronger man in every way that I can. Help me to learn how to be a better American, a better citizen, a better naval officer, a better husband, friend and father - a better Christian. Help me to go home better and stronger in every way that I can - not with this void in my life."

Based on that philosophy he began a series of rigorous physical and mental exercises. He attributes his ability to survive to four kinds of faith; faith in himself as an individual, faith in his fellowmen, faith in his country, and faith in God. These faiths as guiding principles serve him in the changing world since his release as they did during his years as a prisoner of war.

He stressed the point that acceptance and practice of these four faiths:

Faith in himself as an individual
Faith in his fellowmen
Faith in his Country
Faith in God

which sustained him during critical years, are necessary for all individuals to withstand daily problems and emerge successfully.

Captain Coffee has tapes available of his experiences and he may be contacted personally at:

U. S. Navy
Commander in Chief
U. S. Pacific Fleet
Code 32
Pearl Harbor, Hawaii 96860

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FOCUS ON THE FUTURE

By

Robert R. Dye
Director, Program Development Division, YMCA of the USA

You certainly could not expect me to start today without telling all of you how good it is to be home. There is a very special place that is Hawaii, truly a blessed spot and I guess one has to be away - it doesn't seem possible it is 14 years - to realize this. As one travels around the world, all places, and I do a great deal of traveling, I think it becomes more and more real that there is a special charm and uniqueness that Hawaii has that exists nowhere else. You should know that, you who live here, and I who was born here as my mother was, so we are really a part of these islands. Why is this?

Bill Suzuki revealed a little bit of my own personal Hawaiiana when he told you about my grandfather's contribution, but let me tell you about another bit of contribution that my father made. In the early 20's they built a tower at the foot of Fourth Street and they didn't know what to name that tower, so they had a contest and I read the old clippings in the Star Bulletin about how some thought it should be Ameha Tower, etc.; but my father said, "No, there can only be one name that people can see as they leave and as they come. One name that really means all of Hawaii, and that is Aloha." That is what they named the tower and I really think that is what makes Hawaii what it is all about.

I often hear today, as I tell people I used to live and work in Hawaii, "Oh, isn't it too bad they are ruining the islands with all the buildings." I think to myself, "You don't really understand what the islands really mean." Of course the islands look differently than they used to, as all cities look different today, but they will never lose the aloha that is here in all of you people.

It is good to be with old friends, I see them everywhere. The YMCA friends, Dorothy Devereaux, friends from many, many days gone by. It is just so great. It is also good to be traveling with the kind of company I am in here. Eleven of us were in New York two weeks ago having the same kind of meeting with not only people up in the eastern U.S.A., but just as we have had people here from other Pacific Rim and Asian countries; there we had people from Sweden, London, Canada, Mexico, and it was so good. Reverend Wilke, Col. McCahill, John Sevier, John Nesbitt, Janet Pomeroy, Bill Suzuki, Grace Reynolds and June and Mary and Marsha, and all of us really now have the advantage point of seeing two meetings like this come together and share and learn because all of us, and especially me, are learners in this whole area that we have been talking about the last few days. I am not going to say a great deal today. You have heard much. Certainly you saw testament to the faith and courage and patience and trust that Captain Coffee stirred all of us with a few moments ago. That said enough, I think, for all of us. We will remember that a long time. But I am not going to make a lot of very profound statements on what the future will bring, but just repeat, I think, what all of us have said to each other in New York and here in Honolulu in the past few days about some of the things that we have to keep working on.

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Focus on the Future

First of all, I want to start by expressing my personal appreciation to this group of people, this assembled group, for three days of what I think has been very stimulating conversation, sharing of ideas, expressions of commitment, and conviction and very special moments of inspiration. There have been moments of inspiration starting with my friend, Harold Wilke and ending with people like Gerald Coffee whom I had not met before. I am sure that all of you here in Hawaii have felt that our meeting has had a special luster by having present with us the added dimension of Taiwan and Japan and Kuala Lumpur and Australia and Canada. The sharing they did of their programs and their feelings illustrates that we need to create more opportunities for coming together like this for learning and sharing.

What then are some of the recurring themes at this meeting and the last meeting which put a focus on plans and strategies for the future? Over and over and over again there has been the recurring theme, that although we have made some strides, that we must continue to look for ways to get the attention of people who need to understand issues and problems of the disabled and the opportunities we have to help solve many of the problems that exist if only we would open up these opportunities, become aware of them and then do something about them. We need to educate people on a very systematic basis, not a hit or miss kind of thing, but focus on special groups of people: the heads of organizations who have facilities and resources to share, prospective employers who should open up the employment field, the people in government who make the laws and regulations, community volunteers who have the wherewithal to help in so many ways if only they could understand what need exists. We must create specific targets for educating people and then very systemically go about that job. We must involve people who can influence what happens in our cities. What we must work for, the outcomes we would seek, is an organizational renaissance of sorts which would further open up our systems fully and completely to all people in natural and graceful ways. This agenda of education and involvement will require advocates and we must expand our group of people willing to make this a personal agenda.

Speaking personally, I know that I too often have expected one member of our staff, Grace Reynolds, to carry the ball for the rest of us. People come to me and talk to me about this and I say, "Oh, go and talk to Grace". I know now that it has become my job too and the job of all of our staff members to equally share this responsibility and this opportunity for opening up the organization that we represent and others that we can influence. I say "systematic" because it must be more than a hit or miss proposition.

I think we need to do some writing about the issues in our organizational and community concerns. So many times we have ideas in our heads and they stay there. We need to get them on paper and share them and write in our journals and newspapers things that are happening and why we feel that it is important and our personal concerns about what should happen. Only if we share this openly and sincerely will others feel it. We need to advertise our intent, create top position papers and write articles. We need to bring this up to the surface and not keep it submerged.

The first need for the future, I would say - as all of you have said - is educating those who need to know.

I think, secondly, we must come to understand that the resources that we need to get the job done are close at hand. They are everywhere. They are present in every community. Just as you in this meeting have discovered resources and interests that you never knew existed, this is true everywhere, in every community. We tend to work in isolation from each other and we need to understand where the resources are and use them. I remember in our New York meeting of the MAY Congress, one person said, "Unless I can get a grant of some kind, I can't get started in this work". He was immediately challenged by someone else who was doing a lot of creative work who said, "You have the wrong priority. It doesn't start with money, it starts with conviction. If you really want to do something badly enough and can creatively conceive the kinds of things that you would like to do and interpret this, then the resources and the money and the interest will flow from that. It doesn't start by sitting back and saying 'I can't do anything because I don't have a grant'. If you do that, nothing will ever happen."

This has been proven again and again and again. There is great power in the power of an idea at the time that it comes and we need great ideas in this field that all of us are concerned about, but we must make it happen. Resources do not flow in automatically.

Third, and this brings me to one of the most important learnings of the future if we are to advance and make an important impact that is really felt and not just token. We have mentioned the word a couple of times here, but I wonder if we really know the impact of what working collaboratively can mean and by saying working collaboratively I don't mean coming together once a month and doing a little "show and tell" and then going back to our offices. I mean working collaboratively in a sustained way. You have been reminded that Project MAY is a collaboration of twelve national organizations who have come together, designed an agenda, designed some goals, put an executive to work and meets on a regular sustained basis to be sure that agenda is being carried out. The three little program manuals you have in your material were done as a collaborative Project MAY project. All the resources, the ideas came from twelve organizations sharing. I can remember some of our meetings where we read to the blind member of our policy committee chapters of this and she said, "Yes, that's right", or "No, that should be changed a little". She was the expert, she was the person that we were really writing for.

The input that went into this could not have been successfully done if just one person sat down from a limited vantage point and wrote out three manuals. But, working collaboratively, good things happened and they give all of us resources all of us can use instead of all thirteen of us having to sit down and write individual manuals. When we work together, the fruits are all of ours. The collaborative process was never made so real to me as during the early 1970's when some of us started work on the cause of juvenile justice. You saw a film yesterday on status symbols. This was our concern; that hundreds of thousands of young people were being put in prison and literally ruined for life because we don't know what to do with them. Not being able to tolerate a young person who runs away from home or cuts school or something, he is put in jail thinking that would be the answer and, of course, that was the problem. We saw a piece of juvenile justice legislation Birch Bayh had introduced that would humanize the juvenile justice system, that would look at community organizations like the clubs and the Boy Scouts and the Y as places where these kids could be helped and worked with, not the jails. We thought that it was such a beautiful piece of legislation that we would advocate for it. I remember writing testimony, going to Congress, sitting down and testifying before Congress as the YMCA and the Girls Clubs person went and testified. And on it went, all of us from our own little vantage point, testifying.

You know what happened in 1973. The bill didn't get out of the committee. So we sat back and said, "What in the world went on?" We suddenly became a little more sophisticated in the political process where everyone is trying for a piece of that pie. So we said, "What would happen if we brought twelve organizations together and lobbied together on this thing. We formed a collaboration of four organizations and suddenly all the board members, thousands of them in those 12 organizations, became potential advocates calling on Senators and Representatives in their cities, writing and telephoning. We hired a person part-time to help coordinate this effort and suddenly a constituency that didn't exist suddenly existed. In 1974 Birch Bayh introduced this legislation again. This was the time the President was saying, "Too many social programs - cut back, cut back." We know what that means today and we asked the Senator what chance the legislation had this time and he said, "100 to 1. No chance of getting this passed." We went to work and that time when we testified, instead of us coming in with our own little organizational banners flying, four of us sat down and we said, "We represent twelve national organizations, 30 million young people, and we'd like to talk about a cause deep to our heart."

Suddenly the committees stood up and took notice. When the bill came up for passage, the 100-1 shot was passed 88 - 1 in the Senate, and 325-30 in the House; overwhelming passage. The exciting thing that happened next was that this group of organizations said, "Now if we can lobby for legislation; when the money starts flowing out of the legislation, instead of all running for our own little grant, protectively, let us bring together the same group and add another five or six organizations to it and come up with one program and try to get that one. Never before in history has this happened. Several organizations writing a project, willing to be a board of directors and hiring a staff. Only 12 grants were given that year and the first grant came to us. The collaboration for a million and a half dollars was repeated two years later. Why am I saying this? We could not have done it working on our own, but together all kinds of things have happened. This collaboration which became formalized as Collaboration for Youth, last year got an 11 million dollar grant for youth employment programs, and of course, sponsored Project MAY. I say this to you because in communities we have always been used to working on our own in isolated ways, protective ways, seeing the others as competition. Now we realize that we can come together in groups like this and that all kinds of things can happen. So collaboration, I think, as the style of work for the future is with us and those organizations that feel they can make it by going their own way will realize that it is simply not realistic.

Let me make a fourth point. In my own organization the program division that I represent has determined that for the next two or three years one of our most important activities will be the activity that we call "discovery". We find every day that there are hundreds of things that go on in cities around the world that we simply do not know about. Why should we keep discovering the new ways of doing things that someone has already discovered? What we are trying to do is systematically look at places like our cities and in our main meeting in New York of the things that they are doing in

London, the things they are doing in Hiroshima. There are so many discoveries that all of us need to uncover and to make visible and to make acceptable for those of us to work with. We should make an awfully large point at determining how to dig these out and use them. There are processes that are helpful to do this kind of thing. Our mutual discovery process in the future should be directed to looking for all the innovative ideas; all the separate parts that exist to seam the connections, the wholeness, the integration that exists and can come from the many various parts. For those of us who represent large organizations (like our organization, the YMCA, that has programs, resources, facilities, buildings, staff, volunteers) the question, I think, for the future is, how can we really put the disabled on our organizational agenda in a real way, not just a token way? We should recognize that, in so many cases, we are the ones who provide for the handicaps by our willingness to open up to people all the opportunities that they should have. We provide the handicaps. In most cases it is not their problem but our problem, so we must come to realize that all people have a right to participate in what life has to offer, that those with disabilities wish to participate for the same reasons that any person would wish to participate in programs. Yet, in our ignorance and indifference (as one of our speakers in New York told us) retarded children are penned up like little animals, the deaf and the blind continue to be relegated minimal tasks, the elderly are shunned and isolated and all of this is our great loss. The loss of tremendous potential in our society is staggering.

As I have participated in the two MAY Congresses in New York and Honolulu, I remembered some words and phrases in conversation that keep sticking in my mind that give us some clues on the future and the agendas of the future that we must create. One of these conversations dealt with how we must more than ever involve in our planning structures and in our master structures groups who are themselves disabled.

Terry Thompson runs an organization called PHAB. You may have heard of that. I had not until New York. PHAB stands for Physically Handicapped Able Bodied. He is a very innovative, able young man who shared mightily with us in New York. He reported a conversation he had held with a disabled person and Terry asked the question, "Do you think your future is being decided for you?" He received the answer, "No, my lack of a future is being decided for me." A very pointed sentence. Other words I remember, "A society that shuts out people is truly impoverished. We want opportunity, not pity."

Resources are everywhere. Our biggest problem is not the disabled, but the able bodied. What programs do we offer - anything and everything, literally anything goes. I was exposed to a family in New York who had a son who has been in a wheelchair for 19 years, a cerebral palsy patient, whose father and mother believe that that child should be a part of the family mainstream; that anything they do, he should do, who couldn't go to school because he couldn't communicate. Tufts University created a little board for him, a computer of sorts that he can, by moving his head, have sentences light up on that board. People could see that inside that body is a tremendous intellect and intelligence, and because someone took the time to create that means of communicating, he was able to go to public school where he is now. His mother and father, being physical fitness enthusiasts, hike with Rick in the mountains. The achievement that just blows my mind is the parents deciding they would like to enter the Boston marathon and how Tuft University created a wheelchair for Rick contoured to his body with special wheels that could move along the Boston streets. His father, running and pushing Rick ahead in the wheelchair, first had to get in shape by running 15 miles a day or so until he could. They had to qualify for Boston by running a 19 mile marathon. They ran it in time enough to qualify. Also there were little T.V. things they did on the family life that I saw. You see this Boston Marathon, these thousands of runners, and here's Rick in his wheelchair and his father just running full stride up those hills and completing that Boston Marathon in three hours and ten minutes. Some of the runners who finished, these young able-bodied runners saying, "Gosh, I was just going down the stretch when this madman comes by and passes me in a wheelchair." We think such things are not possible.

What programs do we offer these people? Anything, everything. We were talking about mountain climbing and marathons too. You saw Rick's face when they crossed that line. You know that boy was participating in that race just as much as his father was participating. I said to his mother, "Judy, we talk about mainstreaming here collectively. I guess mainstreaming starts in the family, doesn't it?" She said, "Yes, it starts in the family."

It is a tremendous inspiration to all of us to be around people who feel like this. Their consensus is - commitment comes first, not money. I believe that too. Harold Wilke's contribution. Architecture is important, but attitude is of critical importance. The ramp is not enough. Then finally, one speaker repeated the words of Richard Bach of Jonathan Seagull fame. As we talk about all the things that need doing and how hard it is at times like this with money drying up seemingly and so much to do, he quoted Richard Bach in his words, "If you can think it and dream it, you can do it." Aloha!

CLOSING REMARKS

by

Grace D. Reynolds
Director of Special Populations, Program Development Division
YMCA of the USA

As we are about to draw to a close, I'd like to have you just look over your agenda. These are the people, all of you; the people who have performed in leadership roles, you who have participated, who have made the MAY Congress whatever it has meant to you.

We have attempted to sow the seeds so that mainstreaming, integration, normalcy will grow and flourish wherever you may live. It is commitment. It is a belief. It is faith. It is each one of you making the attempt to be creative in whatever way you can be and work with the agency you are with so that people with disabilities may become more a part of our society.

We have shared together. We have learned together. We have talked about a position statement. We have complete agreement that these are the things that we need to say to our boards, our committees, to the people next door, to our own families, perhaps.

But as to the future, the future doesn't start with money and as Bob Dye said and Janet Pomeroy has said, it starts with commitment and a belief in what you are doing. Each one of us can make a difference. I believe that the future is in your hands and I am smiling because I know you are going to do a good job.

Aloha.

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Mainstreaming Activities for Youth

Project MAY

Hotel Ilikai
Honolulu, Hawaii
September 29th - October 1, 1981

DEVELOPING AND COORDINATING COMMUNITY RESOURCES: DON'T PUT ALL YOUR EGGS IN ONE BASKET

Janet Pomeroy, Founder and President
Recreation Center for the Handicapped, Inc.
San Francisco, California

I. The new era of "do more with less" is upon us. Public attitudes toward government spending, increase accountability, management by objectives, computer science, and other factors, are pointing toward ways in which we have to move, if we are to survive. Those of us in California have had a few years of experience in survival after Proposition 13; but I believe that these are very exciting and challenging times. Today, recreation professionals must wear many hats. Recreation is a diversified field fulfilling needs in all aspects of human life. Recently, someone said that the technical skills we need in this day and age include education, advocacy, psychology, sociology, political science, journalism/public relations, grantsmanship, finance and fundraising, secretarial, law, computer science, business, and I have added one other -- the ability to walk on water.

During our almost thirty years of providing community-based recreation programs for the disabled population, we have found ourselves involved somehow in most or all of these technical areas and we have had to learn them through experiences. I think it's because we have always been responsive to the needs of the severely disabled in the community as they arose, and found ourselves evolving into many areas we never anticipated in order to fully meet their needs. For example, as needs were identified, services were expanded to fulfill the need. A chain reaction tended to occur. As new services were added, the need for additional support services was apparent. Following are several examples:

* Referrals of severely disabled persons created the need for skilled social workers to develop intake procedures, case studies, IPP's (Individual Program Plans), and referrals to other agencies.

* The need to serve breakfast, lunch and dinner meant that we had to have a chef and kitchen staff to prepare nutritious meals.

- Enrollment of the severely disabled greatly increased the need for more buses for transportation, and schedules eventually had to be put on a computer.

- When we saw the need to serve homebound persons with terminal illnesses and the frail, unserved elderly, we organized an Outreach program which created the need to learn new ways of training staff involved with death and dying, how to serve persons in their homes, and the use of community facilities for programming.

- Serving deinstitutionalized mentally retarded and multi-disabled persons established the need for medical and technical consultants in vocational rehabilitation, psychiatrists, social workers, and physicians. In addition, there was a need to work closely with new groups such as board and care operators and foster parents.

- The establishment of the first day care program for multi-disabled children and crib-bound children, created the need for more consultants, especially in pediatrics, and others who could help with orientation and training of staff, as well as help to assure linkag with other community services.

- The continued growth of pre-school, day care, outreach and increased enrollment of the deinstitutionalized retarded, clearly showed the need for adapted facilities in the least restrictive environment. This meant the need to design and construct new accessible facilities costing millions of dollars.

- The new facility, with its therapeutic swimming pool and large gymnasium with weight lifting room, created the need for specially trained staff in aquatics and physical fitness, such as CPR, First Aid, adapted equipment, and the chain reaction continues.

Our agency realized that meeting the needs of multi-disabled infants to deinstitutionalized mentally ill/mentally retarded adults and the elderly meant going that extra mile and required the development of additional technical skills mentioned previously, as well as the necessity to work closely with many other agencies in the community who could provide counseling, training, and other support services essential to the growth and development of community-based services for severely disabled persons.

Over the years, we have found that there are many resources available to both public and private agencies for establishing recreation programs for the disabled and the expansion and/or support of ongoing programs, and we believe that they exist in every community. However, locating and coordinating these resources is a continuing process - but it is also very challenging, inspirational and enjoyable!

I would like to mention four techniques we can use in developing community awareness and explain briefly how we have used them. They are educate, advocate, demonstrate and politicate.

Education:

a. Educating local and state officials

Communities around the nation are becoming more and more aware of the disabled and their needs and, or course, the International Year of the Disabled has helped tremendously. However, I think that we still have to continue to educate at the local, state and national levels, because education is a slow process. It has taken many years to try to educate our community and we are still in the process of doing that.

We attend community meetings, such as those held by the Board of Education and the Recreation and Park Department, to educate commissioners and others at the local level, and we are constantly involved with state legislators to inform and educate them of the needs and rights of disabled persons. When I first started the Center, one Recreation and Park Commissioner in particular used to say "disabled people should be in state institutions, not in the community." He was on the commission for eight years, oppposing our programs. He couldn't see how recreation would have any meaning for disabled persons.

This attitude presents another very real problem, which is the fact that many people still don't understand the word recreation. We must still interpret "recreation" as we see it, in promoting the growth and development of all persons, including the disabled. We have a situation now in Califoria where the State Developmental Disabilities has put recreation at the bottom of the list in terms of priorities for funding. I have talked with legislators recently who don't have the slightest concept as to what recreation is or does for people, especially for disabled persons. They think of it as a token activity particularly to keep such individuals as the mentally retarded from just walking the streets.

b. Educating professionals

We still must interpret recreation for the disabled as a need and a right, especially by stressing equal participation by everyone. Too many programs emphasize the difference between disabled and non-disabled by offering free admission to theatres or concerts, conducting a "Handicapped Day" or other token activities. In an article from the Institute on Attitudinal, Legal and Leisure Barriers, the author states:

> "Providing opportunities for full participation by disabled individuals in community events, including recreation, social and cultural activities, requires action on many levels. It is not enough to provide special recreation programs through local voluntary health agencies or through the local recreation department. All of the activities in the community must be made accessible, programmatically, as well as architecturally, to disabled individuals -- not as a special gesture, but as a community action to include all citizens in local activities. This action is also a recognition of disabled people as viable, independent, tax-paying community members. Participation by disabled people in all levels of community activity (local boards, planning committees, and advisory groups) is an absolute necessity for achievement of the goals of full participation and total rehabilitation. Rehabilitation professionals and community agencies must work closer together to make comprehensive rehabilitation and independent living a reality." (1)

Some professionals believe that all disabled individuals need specialized recreation services and refer them only to agencies that provide such services. While many disabled people do need such specialized assistance, many others could enjoy the wide range of recreational opportunities available to the general community. What may be needed is a careful assessment of client interest and abilities, followed by support services as indicated. One rehabilitation counselor in Sacramento, California, at Resources for Independent Living, follows this process and works with therapeutic recreators to help the client develop the skills needed to participate fully in general experiences. Generalists and specialists need to work together to provide a full spectrum of services.

Emphasizing the special needs of disabled individuals for specialized programs, special and expensive equipment, sheltered environments, and highly trained therapists, tends to discourage the generalists in community recreation and makes them feel unqualified to work with disabled people. The generalists' expertise and the fact that there are so many of them already in the community makes it essential for them to be involved. Moreover, as more severely disabled persons are deinstitutionalized into community living, community recreators must be ready to serve these persons unless more private agencies are organized to do this.

Fortunately, several outstanding pre-service and in-service programs have been funded by the Office of Special Education, U.S. Department of Education, to develop ways of preparing general community recreators to serve special populations. Some examples are as follows:

- The Department of Community Affairs, New Jersey, offers an in-service training project "to implement a cooperative in-service eduction system to promote the development, implementation, delivery and advocacy of recreation and leisure service for handicapped persons within the community of New Jersey."

- Project MAY (Mainstreaming Activities for Youth) designed to work with national and regional structures of major youth serving organizations and agencies, and to share the principles and concepts of providing opportunities for disabled youth to participate in programs and services provided by youth serving groups.

- STAR - Staff Training for Adapted Recreation, in Miami, Florida, designed, implemented, evaluated and disseminated an in-service training model. The target audience is general municipal park and recreation personnel in order to increase the number of disabled children and youths who are able to participate in less restrictive leisure time activities.

c. Public Relations: Educating the News Media

By order of the Federal Communications system, T.V. and radio must allow so much time for public service spots. This is usually called assertainment of community needs. Each year we meet with representatives from the media to discuss the current and future needs of the disabled. Assertainment meetings are held frequently by T.V. and radio, and several meetings of this kind have been held at our Center.

As a result of getting to know these people, one T.V. station made a 3-minute spot showing our Center with our logo, which is used on all stations; and sometimes on prime time programs. The news media can be very effective in educating the community toward acceptance of disabled persons if they are properly educated and guided. Today the news media is willing to televise human interest stories of the most severely disabled individual. Now, there are many television documentaries on disease, disabilities, injuries and rehabilitation, and other areas that has had a tremendous impact on public attitude.

Several years ago, a local T.V. station selected one of our most severely disabled young adults to show him going to work, and in several phases of his personal life, including recreation. It was very well done and helped to show the general public the ability side of a severely disabled individual.

Advocacy:

WE must also serve as advocates at local, state and national levels for recreation for the disabled. As professionals, we have a responsibility to keep the community informed -- city officials, news releases, annual reports, special events. As we know, historically parents, and the disabled themselves, have been the best advocates of most services for the disabled, including recreation. Parent groups have been instrumental in initiating recreation programs for the disabled, and are still essential. Consumers have heretofore directed major efforts to jobs, accessibility of facilities, housing and other issues critical to survival. However, recreation is gaining more attention.

The Center has found that parents and consumers are the best advocates at local and state levels, and certainly we have seen the effectiveness of consumers at all levels. For the past five years, parents and consumers have been working with the Center as advocates to keep the City of San Francisco from building a sewer nearby the Center. Both groups have been very effective and we are winning the battle.

Another group of successful advocates are members of our Board of Directors. It is especially important to have Board members who have some clout in the community and are recognized for their strong leadership ability. One of our best advocates is a board member who is very much respected in the community, and is especially well known at City Hall. This year, he was appointed by the Mayor as Chairperson of I.Y.D.P. for the City and County of San Francisco.

Demonstration:

The experience of the Recreation Center has shown that continued exposure of participants to community resources serves two purposes. One is the skill development and increased self confidence on the part of disabled individuals. The other is the increased acceptance of community members. As the community sees the ability side of disabilities, fears and stereotypes are reduced. We have also found that if we can get people to visit the Center, we can sell the program. Once an individual sees disabled persons enjoying and participating in activities at the Center, they want to help.

We have many methods of getting the general public to visit the Center, primarily through special events. For example, we have an annual Thanksgiving dinner which we have held for 29 years. The primary purpose is to thank our donors, volunteers, city officials and all who have helped us. The dinner is so popular that everyone wants to come, including the city officials; i.e., Mayor, Supervisors, Commissioners. State legislators also attend.

We also have many events throughout the year such as a carnival, winetasting, holiday parties, square dances, casino night, and other events, where many persons from the general community are invited.

II. The Bread Game and Its Politics

I started the Center in 1952 under a small grant in aid from a foundation. The grant lasted 2½ years and after that I had to raise the funds through community support. I avoided involvement in politics for twelve years, until I realized that I would have to become involved in order to survive. The San Francisco Recreation and Park Deartment had given us the use of an old swimming pool building. The top floor had been a restaurant over the swimming pool, but the restaurant had been closed for a long time, and wasn't being used. The Department gave us the use of the building for $1.00 per year, with heat, gas and lights. From the inception of the Center, I felt that the Department should help us financially or include the project in their regular program. During the twelve years of struggling for support, we went through the proper channels three different times to ask for their assistance. Each time, the Commission turned us down. On the last request, they made a study that lasted four years. At the end of this four year study, they said they could do no more than to continue to loan us the building with heat, gas and lights.

Fortunately, I met a state senator who showed me the politics of how to change their minds. It was a simple procedure of using some of the senator's contacts to have the news media do a series of articles showing the Center as a struggling agency, providing a needed service for severely disabled, with private funds, that was rightly the responsibility of the Recreation and Park Department, who at that time had a budget of some 15 million dollars. The efforts of the news media gained city-wide attention, which was especially focused on City Hall. Ultimately, the Department called and said, "Get the newspaper people off our backs - and we'll help you." The Department never wanted to include us in their regular program, but did agree to purchase services from us on a contractual agreement. You can beat City Hall if you have political knowhow. We now have a public-private partnership that has worked very well for the past 17 years.

From our experience, we have learned that it is absolutely necessary to become politically involved at local, state and federal levels of government, as an advocate for recreation for the disabled; especially if you are using federal, state and local funds. There is no alternative to dealing with government bureaucracy if one wishes to obtain financial assistance through local, state, federal or federal-state programs. This requires a continuing process and as the politics change, the financial resources change. This makes it necessary for an agency to keep a constant watch on every area affecting these resources at all levels of government.

For example, we found we needed to be involved in the development of state-wide plans for the disabled.

Need for Involvement in State Plans:

About 15 years ago, we participated in setting priorities at the local and regional levels in developing a state-wide plan for the mentally retarded (now known as the developmentally disabled.) We attended many meetings and verbalized the need for recreation programs, especially for the previously institutionalized adults. As a result, recreation and/or day activity programs for adults is still a top priority for the regional and state plan for the developmentally disabled population in the State of California. This was achieved through a combination of education, advocacy, demonstration and politics.

Lobbying:

* Eight years ago, California reached its ceiling on allocation of federal funds. For the last six years, the state had to augment the Title XX monies to allow services to be maintained and with a cost of living increase. In 1977, the governor decided not to augment these funds. Our agency, together with other agencies, got together and demonstrated in Sacramento. Our staff, with about 60 participants, sat in the Governor's office for two nights. The augmentation was given by the State, and since that time, we have been asked to please not bring any of those severely disabled people to the Governor's office again.

* In 1979, we helped to form a coalition of all agencies serving the disabled called the West Bay Coalition, to reinstate developmentally disabled funding at the state and regional levels. Our staff attended many legislative meetings in Sacramento and took bus loads of participants. It's hard for a senator to make a decision against disabled persons when they are sitting on the front row of a large audience of advocates. Recently, these funds were reinstated and we were not cut back in our contracts, as expected.

We have found that if you're receiving any governmental funds for programs, there are many things you must do. On a year-round basis, we must:

* Know the legislators - understand the legislative process.

* Meet with legislative aides to keep them informed about program needs; ask for their help in researching some piece of legislation or for tips on how to approach legislators; and have them check on bills, laws, resolutions, deadlines, etc., in Sacramento. This means setting up many meetings, luncheons, telephone calls, etc.

* Write letters to legislators, send telegrams, visit their offices in Sacramento - Lobbying is continuous. We must also attend many meetings in the community concerning our contracts.

Contracts

I learned from the Bread Game and its politics that you don't put all your eggs in one basket. The Center presently has six contracts for funding that have proven to be very successful for ongoing financial support. They are as follows:

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1. The San Francisco Recreation & Park Commission allocation is now used as matching funds for federal funds in Title XX monies. For every dollar we get from them, we get $3,000 from federal funds. Our allocation is now $350,000.

   After submitting a budget:

   - We attend a meeting when the budget request is presented to justify the need for a certain amount.
   - We then follow the request to City Hall where we meet with the Mayor's Aide in charge of Recreation and Park budgeting to ask him not to cut the allocation.
   - We contact the Mayor to ask that the full amount remain in the budget.
   - We appear before the Finance Committee of the Board of Supervisors to justify our need and ask them to approve the total allocation.
   - We meet before the full Board of Supervisors to justify, defend, or otherwise make sure that the full amount of the allocation for the Recreation Center in the Recreation and Park budget remains intact.

2. Department of Social Services is our largest contract for Supplemental Security Income (SSI) Title XX monies. Recreation and Park is used as matching funds. This year the contract is $750,000. We must go through the same procedures as with the Recreation and Park contract; i.e., the Commissions, the Mayor, Supervisors, and others at City Hall.

3. Currently we have a contract with State Department of Education, Office of Child Development, for pre-school and day care for severely disabled on a year-round basis. We are one of six agencies in the whole state providing these services. This contract was definitely obtained through politics.

   We have many meetings with other agencies in the state who have the same kind of contract, because each year it looks as though we will be cut back and/or have contracts terminated. Recently, the six agencies receiving these funds got together to finance a state child consultant to lobby for us. The consultant advises us when to appear, before what committee at the state capitol, what materials to have, and what to say. Our state senator from San Francisco has helped us considerably, and now we have the Speaker of the House supporting these programs. It looks as though we will have permanent financing on this particular contract.

4. Regional Center - We now have a contract with a regional center in which the State Developmental Disabilities Council determines the rates. We must lobby continuously for these funds. At present, we are lobbying for higher rates to cover the costs of developmentally disabled clients. The state has just been sued by an Area Board for their low rates for providers.

5. Commission on the Aging - This contract serves the elderly in 17 residential homes. The contract has been in effect for only two years. It covers 90 frail elderly who are in great need of socialization programs.

6. The State Food Program is another contract that covers the cost of food for children up to 18 years of age. It is a very complex program, with lots of paperwork, for $5,000 per year.

While there are many politics involved in this type of funding, the public-private partnership approach has been very successful. At present, there are many proposed changes in federal and state funding that will, no doubt, have an impact on recreation programs for the disabled.

Municipal recreations authors Howard and Crompton, in their book "Financing, Managing and Marketing Recreation and Park Resources" have stated very well the need for public-private partnerships as follows:

> "Public recreation and park personnel must move to active leadership roles in the community, for assistance from the private sector will only come if we are aggressive. Personnel have to be doers who make things happen, not excusers, who find excuses for not trying or making the effort -- raising additional resources is not always a problem; sometimes it is a symptom. The problem may be the inadequate image of public recreation and parks and the lack of a committed support constituency. If the agency is visible, vigorous and successful, it is likely to enjoy public support which will help it secure its fair share of the substantial private assistance available. Building more contacts is the key. By involving more people, more resources seem to emerge and fresh new avenues not previously considered become available."

Private Funding:

There are some politics involved in raising private funds, but not nearly as much as in working with the government bureaucracy. It does help to have some contacts and/or track records with foundations and corporations. We have to raise 27% of our budget through private resources. This means we must have expertise in grantsmanship which includes knowing how to do research, how to approach the private sector, how to write proposals, obtaining support letters from community agencies, report writing and follow through with quarterly, annual and final reports.

In approaching the private sector, especially foundations, we have found that there are millions and millions of dollars to be tapped. The University of California, Berkeley, stated recently that "more than 20 million dollars an hour is given to non-profit organizations, by foundations, corporations and governmental agencies."

Some community foundations, especially the very large ones, change their priorities from time to time. One foundation in San Francisco used to give heavily to education, recreation, humanities and environmental and civic causes. Now they have changed to minorities programs, burn centers, drug programs, death and dying, alcoholism, gay rights, planned parenthood, and Gray Panthers (elderly.) Very recently, this foundation has set priorities for proposed projects where two or more agencies must be involved, and will look closely at how supporting a certain project would help the total community in some positive way. Agencies seeking funds have to adjust to these priorities by developing creative proposals that will fit the foundations' guidelines.

Service Clubs and Fraternal Men and Women's Associations

A large portion of our private funds are contributed by men and women's fraternal organizations and service clubs, and our Parents' Auxiliary. Most of these groups use the Center facilities for raising funds through such activities as pot luck suppers, carnivals, square dancing, crab feeds, Casino Nights and others. An annual benefit horse show, which is conducted by the Sheriff's Posse, has been a very successful fundraising event. All of the Center's buses are donated by service clubs and/or individuals. One individual donated 3 buses.

Wills and Bequests

Wills and bequests are marvelous ideas to pursue. One way is to contact all attorneys, and trust departments in banks, in a city. Names and addresses can usually be found in telephone directories. The Center has had a number of wills which were left in trusts. We had a "Mr. Anonymous" who was looking for an "honest" agency to help financially and to leave his money to when he passed on.

Corporations ("National Directory of Corporate Charity")

16 million U.S. companies in the United Stated donated $2 billion to charities in 1980. Most corporations have a foundation; if not a foundation, they have a Contributions Committee. We have seen some very interesting things happening with corporations. Some of them are becoming more aware of their role in helping non-profit corporations within their communities. More and more, corporations are developing what they call C.I.T. (Community Involvement Teams). These teams are made up of employees who visit charitable agencies to see how they can help. When they find one they want to help, they decide on a suitable fundraising project. They then commit themselves to raise a certain amount of funds...whatever they can't raise is matched by the company foundation. One example in San Francisco, which is also around the world, is Levi Strauss.

Levi Strauss has a C.I.T. team and this year they selected the Center to support. They committed themselves to raise $30,000 to replace our floor in the multi-purpose room. The team coordinated their efforts with the Hyatt Regency in San Francisco, who agreed to contribute all their funds from Tea Dancing, in addition to the wishing fountain where coins are dropped daily. Their theme was "Panning for Gold". On the opening day of the project, all of the T.V. cameras were there to televise our severely disabled children with "prospectors" panning for gold (our staff). The managing directors from Levi Strauss were there and the story made the T.V. evening news, the newspaper and other media in San Francisco.

Another example of how corporations are working is Chevron (Standard Oil) who agreed to put up $32,000 to sponsor a city-wide runathon to benefit the Center, in cooperation with a local T.V. station. This took one year to organize. We didn't raise as much money as we had hoped, but we got a lot of visibility on T.V. and we learned from our mistakes. We hope to try again next year.

Marketing

If we have the budget cuts we have heard about, I believe that future survival will be learning how to sell our products, especially to the private sector, in creative, unique ways. Creative marketing in recreation will, I believe, become very prevalent in the 80's, particularly in private agencies, as well as public agencies. The Center has actually been marketing specific programs for years, although we didn't call it that.

Successful marketing is very much tied in and related to good public relations know how. Following are some selected examples of how we have marketed some of our programs, and equipment and supplies:

a. We write a brief proposal for adopting and supporting a specific program, for around $20,000 to $50,000 per year. Some examples are as follows:

- Mainstreaming After School Recreation programs for disabled children.
- Day care for autistic children.
- Outreach for senior citizens.
- Pre-school programs for severely disabled children.
- Day Camp for severely disabled children.
- Homebound recreation for terminally ill school children
- Weekend Wilderness Camping, i.e., trip to Yosemite, trip to Tahoe for canoeing.

* Water ballet
* Christmas parties
* Camperships
* Parent/Child swim program

We write these up in a promotional package, and contact foundations and corporations.

b. Provide a van for Transportation - Donor name, letters each year from each bus; can be a memorial.

* Service club
* Individual
* In honor of, etc.

c Promote the need for 10,000 gallons of gasoline to fill our gas pump.

d. Furnish an activity room, gymnasium, physical fitness appartus -- table, chairs, play houses, sand boxes.

e. Wish lists - projectors, typewriters, video tape

III. Sharing and Coordinating With Other Agencies

Based upon the Center's 29 years of experience, we believe that every community has the resources for initiating and/or expanding recreation programs for its disabled. Every community has dedicated volunteers willing and eager to help either in direct services, or through contributions, and many of these persons are often seeking an agency to support even though they may never have been involved before with a disabled person. Almost all communities have voluntary health and welfare agencies, and it is essential to cooperate, and coordinate with local, public, and private health, educational, rehabilitation and other related agencies in developing community resources for the disabled. This is necessary for survival, especially if governmental funds are being used. This avoids duplication of services among agencies, and brings a force together to lobby for the good of all agencies.

When I first started the Center, I found that agencies serving the disabled had no communication with each other. There was no forum for agencies working together to share experiences, information, or to coordinate services. We now have a Developmental Disabilities Council, established about seven years ago, which provides us with an opportunity to work together, to share experiences, information and support. We also have a directory listing all service agencies within the City and County of San Francisco.

Today, many community agencies are consolidating their services, facilities, financing and staff. The Center has, for years, shared its resources with other agencies. For example, the Center:

- Shares all of its information and materials, nationally and internationally.
- Shares its facilities for meetings, forums, workshops, seminars, conferences, special events, and fundraising activities.
- Provides transportation for eleven other agencies serving the disabled, such as Easter Seal, ARC, UCPA, and others; in workshops, day care centers, schools, independent living centers, and others. This is done on a contractual arrangement.
- Schools for disabled use our swimming pool and gymnasium.
- Serves as a drop off center for school children whose parents are not home.

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- Provides reverse mainstreaming which is a continuous, on-going program for able and disabled children and their parents in swimming programs. "Teaching parents to teach their children to swim", ranging from infants, 3 months old and up.

- Serves 150 therapeutic swimmers from the general community who are referred by their physicians for week warm water swimming. These are persons who have had strokes, suffer from arthritis, burns, etc.

- Has developed a Kindergym for able and disabled children in the gymnasium.

- Is exploring a new concept which is contracting with other counties (Recreation & Park Departments) in satellite programming for recreation for school children.

Some of the agencies sharing its resources with the Center are as follows:

Staff Training and Consulting Services

Department of Vocational Rehabilitation

Universities and Colleges

Girl Scouts - Boy Scouts

Junior League

Community Services

The Management Center

Department of Social Services

The Foundation Center

Commission on Aging

Facilities and Programs are shared by:

Recreation and Park Department

The San Francisco Unified School District - Transportation

YMCA - Resident Camp

YWCA - Swimming

Girl Scouts - Boy Scouts

Jewish Community Center

Community College District

Commission on Aging

IV. A 20-Year Plan to Respond to Trends - Projected Needs Expansion of Programs for the Elderly

National statistics show that the adult population is increasing very rapidly and it is estimated that by the year 2010, there will be 40 million elderly people in the United States. The majority will not be institutionalized. Only 5% are in nursing homes at any one time, which means that 95% will remain in the home and in the community. The current and future needs for this population, as outlined by the Administration on Aging, will be the establishment of multi-purpose centers that will provide, through a comprehensive and coordinated system, for social services, nutrition, transportation, outreach information and referral, homemaker services, and transportation.

These needs can only be fulfilled through cooperation among all community agencies and organizations in advocacy, identification, political involvement, coordination or services, and the provision of recreation and socialization programs.

In order to continue to meet these needs of the elderly population, the Center has developed a 20-year plan, part of which calls for the construction of a day care multi-purpose Center for the aging. The program will emphasize socialization activities which will develop self-help skills, improve physical functioning, enhance self esteem, acquire and share new interests and hobbies, through such activities as physical fitness, swimming, gymnastics, cooking, cultural arts and hobbies, music, dance, parties, and trips and excursions into the community.

Expansion of Services for the Mentally Ill/Mentally Retarded

The mentally ill/mentally retarded is a growing population due to better assessment and identification, and because some of the persons have been released to the community from state institutions. A recent State of California survey indicated that there are 240 mentally ill/mentally retarded ready to return to the San Francisco community to live in board and care homes, provided they can be asssured of recreation and socialization programs that will include them five days each week.

The Center plans to construct a day care facility for the mentally ill/mentally retarded where they will have access to the swimming pool, gymnasium, socialization and nutrition programs at the Center five days each week. Here, they will be taught the basics of self-help and independent living skills such as cooking, personal grooming, adult education as needed, and socialization skills. Leisure education related skills will also be an intergral part of the program to facilitate the participants' independent leisure functioning.

Continued Mainstreaming of Severely Disabled Children and Adults

One of the primary goals of the Center, for over a period of 30 years, has been that of (mainstreaming) integration of the severely disabled into community-based programs, with the non-disabled citizen. This has required a specially designed program of education, training of staff, and shared resources in order to provide a continuum of services to the disabled population.

Because the Center has facilities such as the swimming pool, gymnasium, and a large recreation center building (equipped with a stage, activity rooms, etc.), the staff has encouraged "reverse mainstreaming" of the non-disabled population. For example, parents of non-disabled children and their child, and parents of the disabled child and their child, are taught swimming for infants. Parents of both groups are taught how to swim and how to teach their children to swim. These programs are conducted several times each week for groups of 15 to 25 disabled and non-disabled children and parents. In addition, a "Kindergym" program for disabled and non-disabled children is conducted in the gymnasium on a weekly basis. This is a parent participation program in which children learn gross motor and social skills as they explore their environment, meet new friends and enjoy diverse, colorful play equipment.

Need for Education and Training of Persons in Recreation in Developing Countries

Because of almost 30 years of service, the Center is recognized nationally and internationally as a pioneer and a model in developing recreation, education, socialization, and health care programs for the severely disabled of all races and creeds. The Center has not only successfully pioneered a wide variety of programs to fit the needs of all types of severely disabled individuals from infants to the elderly in the City and County of San Francisco, California; but it has shared its expertise nationally and internationally through lectures, workshops, conferences, seminars, films and through voluminous written materials.

Since the Center is partially supported through federal funds, governmental agencies at all levels are aware of its programs and use its facilities as resources for information and referrals. As a result, individuals and groups from around the world visit the Center almost daily. On a yearly basis, a minimum of 25 college and university students spend an entire semester at the Center where they undergo an intensive internship in all phases of the program which is a requirement for their undergraduate and graduate degrees.

As a result of the national significance of the Center's program, the heavy demands upon the Center for its use as a unique laboratory for training professionals, students, volunteers and others, ahs grown beyond all expectations and well beyond its ability to fulfill these requests in its present facilities and programs.

In order to meet those needs, the Center is planning to build an educational training and conference facility with dormitories, where low income and international students, professionals, recreators, educators, and others could stay for a semester of studies or a weekend conference. In the past, many students from various parts of the United States and abroad have made inquiries about training and education at the Center, but have found that the cost of motels and hotels was prohibitive for their incomes, and they were, therefore, unable to pursue their training opportunities.

Currently, and in the future, the recreation profession greatly needs individuals from a variety of ethnic backgrouns to better serve the total needs of the community. The availability of education and training at the conference site would encourage these individuals to enter the profession and to develop expertise in this area.

The Center also has plans to develop and publish a wide variety of handbooks for initiating and implementing recreation programs for the disabled and to disseminate these materials nationally and internationally. In addition, some of the current staff of the Center will be serving as International Consultants. These are staff who plan to take a leave of absence for a year or more to travel, to lecture, and to assist wherever needed.

Training opportunities available now at the Center are listed in Appendix A. Examples of professionals who have visited the Center are listed in Appendix B.

Conclusions:

Serving persons with multi-disabilities, and those who have been institutionalized for long periods of time, means getting involved in transportation, liaison with community agencies, nutrition, social services, developmental needs of children, and educational aspects essential for them to gain maximum benefits from recreation and leisure time pursuits.

It is also necessary to educate, advocate and to become politically involved, in order to develop community awareness and financial support. We have to learn how to package and market our programs with the private sector, such as foundations, corporations, and service clubs, and it is essential to communicate, cooperate and coordinate with all other public and private agencies serving the disabled.

Each community must identify the needs of its special population, and examine the resources to meet those needs. Every community has the potential of starting or expanding programs. The key is commitment to the rights of disabled individuals, recognition of their needs and a determination to provide services to meet those needs. Begin small, with a focus on quality programs, not on numbers. Only through quality programs will disabled individuals be able to reach their potentials and take their place in the mainstream of society.

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APPENDIX A

EDUCATIONAL EXPERIENCES

offered by the

SAN FRANCISCO
RECREATION CENTER FOR THE HANDICAPPED, INC.

Visitations:

Individuals and agency representatives are welcome to arrange a tour of the Center at any time. Visitors will receive an overall orientation, a tour of the facility, an opportunity to talk with staff and to observe programs. The scheduled visit can be adapted to meet the needs and expressed interests of individual guests. For example, if you are most interested in Aquatics programs and facilities, the majority of your time can be spent in this area.

Volunteer Placements:

Through our well-developed volunteer program, individuals can arrange a "hand on" experience in any one of the agency's five Divisions. Assignments to Division programs can be arranged for any day of the week, Monday-Saturday. Volunteers interact in the program unit as part of the staff team, assisting to carry out pre-planned recreation activities including Aquatics, Gym games and sports, weight room workouts, Arts & Crafts, Music & Drama, special events, and much, muc more.

Volunteers are given an orientation to the agency, including film and tour. Their hours are kept in a permanent record file along with a general evaluation of the volunteer's work in his/her assigned area. The Coordinator of Volunteers can include hours, assignment requirements and evaluation comments in a letter of recommendation or referer upon request from the individual volunteer.

Field Study Placements:

Field Study Students frequently contact the Coordinator of Volunteers for placements which are required by their school, college or universi Field Study Placements are usually individualized according to the requirements of the specific instructor or department curriculum.

Generally, the student attends a volunteer orientation, followed by a personal interview. During the interview the student and the Coordinator of Volunteers can review the field study requirements and make necessary arrangements to facilitate an appropriate placement.

Field Study students have applied to the Center individually and as groups for single or multi-day placements, ranging from several weeks, a regular three month semester, or for an extended period of time.

Internships:

The Center offers a structured one semester internship which is certified by the California Park & Recreation Society, and conforms to the

National Therapeutic Recreation Society internship requirements. The agency can accommodate six interns per semester including summer session. Students from all over the world, studying in a variety of disciplines, have participated in the Recreation Center's intership programs. Students are placed in each of the five program Divisions where they participate in program planning, implementation and evaluation as part of the staff team. Internships also include orientation to general agency operation including Board role and function, budget and finance, grant writing, facility management, transportation coordination, personnel policies and procedures and supervision.

How to Arrange for Educational Experiences:

To arrange for any of the above experiences, contact Betty Miller, Coordinator of Volunteers. Identify what experience you desire and projected dates. Betty will make the necessary arrangements or send you the appropriate applications.

Betty Miller
Recreation Center for the Handicapped, Inc.
207 Skyline Boulevard
San Francisco, CA. 94132

(415) 665-4100

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APPENDIX B

EXAMPLES OF COUNTRIES WHO HAVE VISITED THE RECREATION CENTER IN RECENT YEARS

The Center has enjoyed visits from hundreds of professionals and private citizens from around the world, including medical doctors, nurses, administrators from human service and rehabilitation agencies, educators, dieticians, government officials, physical educators and recreation professionals.

Outlined below is a list of the various agencies who have sent representatives to the Center, or who have requested and received information.

EUROPE:

Social worker, Centre de C-Aiche, Verneuil, FRANCE
Social Director, Ministry for Family, Youth & Sport, BERLIN
Head teacher, Glencryan School, Cumbernauld, SCOTLAND

JAPAN:

40 social workers
30 Special Education teachers
One language specialist
Deputy Director of HOme for Low Developmentally Disabled, and two reporters
Group of 20 social workers, counselors and nurses
Group of seven participants in Social Welfare Seminar held in San Francisco: Child care worker, Clinical Psychologist, Medical doctor, Case worker for mentally retarded, Senior child care worker, Administrative staff member, Braille Library rehabilitation trainer for blind, graduate social worker, and interpreter.

Director of Social Welfare, Yokohama, JAPAN

CANADA:

Teacher from Recreation Administration Department, Mount Royal College, Calgary, CANADA. Makes an annual visit to the Center and stays at the Center for four days, working in program along with staff.

VARIOUS OTHER COUNTRIES

Director, Department of Special Education, Santiago, CHILE
Director, Rehabilitation Institute for Crippled Children, Santiago, CHILE
INDONESIAN Consulate representatives
Group of French speaking doctors and Ministers of State from several AFRICAN countries: MOROCCO, CAMEROON, ETHIOPIA, ALGERIA, THE CONGO.
President, Egyptian Society for Mental Health, EGYPT
Columnist, China Times, TAIWAN
Dance Instructress, Kingston, JAMAICA
Doctor, Department of Human Movement & Recreation Studies, University of WESTERN AUSTRALIA
Director, Instituto de Rehabilitacion Infantil, Santiago, CHILE

Requests for Information and/or Literature

EUROPE:

Social worker, Greenhill House, Cheshire Home, Avon, ENGLAND
Social worker, George Bell House, London, ENGLAND
Director/President, Multiple Sclerosis Society, London, ENGLAND
Professor, Technische Universitat, Raum, GERMANY

AUSTRALIA AND NEW ZEALAND:

Recreation Officer, Royal North Short Hospital, Artarmon, AUSTRALIA
Section Organizer, Queensland National Fitness Council for Sport and Physical Education, Brisbane, AUSTRALIA
Research Coordinator, Australian Council for Rehabilitation of Disabled, Surry Hills, NSW, AUSTRALIA
Social Worker, Institute of Social Welfare, Melbourne, AUSTRALIA
Welfare Officer, Civilian Maimed & Limbless Association, Camperdown, AUSTRALIA

VARIOUS FOREIGN COUNTRIES:

Member, Documentation and Information Center, Fundacio Para el Desarrollo de la Educacion Especial, Caracas, VENEZUELA
Member, Newfoundland and Labrador Recreation Advisory Council, St. Johns, NEWFOUNDLAND
Instructor, Lakshmibai National College of Physical Education, Saktinager, INDIA
Director, Fundacio Para Servicios a Nino, Santurce, PUERTO RICO
Counselor, Recreation Council for Disabled, Halifax, NOVA SCOTIA
Social worker, Instituto de Pedagogia Terapetuica y Educacion Especial, Bogota, COLUMBIA
Worker, St.Giles Association for the Handicapped, Durban, AFRICA
Deputy Director General, National Iranian Society for Rehabilitation of the Disabled, Tehran, IRAN
Social Worker/Nurse, Institute Integral del Ciego, La Plata, ARGENTINA

CANADA:

Parks & Recreation Director, Glace Bay, NOVA SCOTIA
Teacher, London South Secondary School, London, ONTARIO
Rehab worker, Sunnyhill Hospital for Children, VANCOUVER
Coordinator, Special Programs, Burnaby, BRITISH COLUMBIA
Rehab Supervisor, Department of Physical Education, Moncton, NEW BRUNSWICK
Social worker, Ministry of Community & Social Services, Toronto, ONTARIO
Recreation Coordinator, Saskatchewan Association for the Mentally Retarded, SASKATOON
Coordinator, Recreation Curriculum, Acadia University, Wolfville, NOVA SCOTIA

Requests for Informaton and/or Literature

CANADA continued:

Aquatic Planner, Alberta Culture, Youth & Recreation, Recreation Services to Special Groups, Edmonton, ALBERTA
Centre de Documentation, Formation des Maitres, Montreal, QUEBEC
Program Director, Camp Caroline, Edmonton, ALBERTA
Supevisor, Recreational Development for the Handicapped, City of Grande Prairie, ALBERTA
Volunteer Coordinator, Surrey Parks & Recreation Commission, Surrey, BRITISH COLUMBIA
Resource & Information Officer, Kinsmen Centre for the Handicapped, SASKATOON
Assistant Psychologist, Department of Health & Social Development, Brandon, MANITOBA
Supervisor, Special Services, Calgary Parks & Recreation Dept., Calgary, ALBERTA
Handicapped Program Supervisor, Y.M.C.A. of Greater VANCOUVER
Department of Recreation, University of Waterloo, Waterloo, ONTARIO
Consultant Psychologist, London, London & District Crippled Children's Treatment Center, London, ONTARIO
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Mainstreaming Activities For Youth

Dallas/Ft. Worth Airport

Irving (Dallas), Texas

February 1-3, 1982

Mainstreaming Activities For Youth
(Project MAY)

A Project to assist youth serving agencies in planning, developing, implementing, promoting and evaluating a collaborative program to mainstream handicapped youth in regular programs.

P.O. Box 1781, Longview, Washington 98632
Phone: (206) 577-0243

PROJECT DIRECTOR: GRACE D. REYNOLDS
PROJECT OFFICER: WILLIAM A. HILLMAN, JR.

AGENDA

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Irving (Dallas), Texas 75062
(214) 255-7147

February 1, 1981 - Sunday	ROOM	SESSION
10:00 a. m. - 1:00 p. m.	Foyer area	Registration
12:00 noon - 1:45 p. m.	Mexico 2	Staff briefing lunch
		SESSION I
2:00 p. m. - 2:30 p. m.	France & Japan	Opening - Introductions
2:30 p. m. - 3:00 p. m.	"	Keynote address The Inclusive Mainstream Allen R. Sullivan, Dallas Independent School District
3:00 p. m. - 3:45 p. m.	"	Consumer Panel-Parent Panel A Consumer's Point of View About Mainstreaming Panel Jamy Black McCole, Moderator, United Cerebral Palsy Don Drewry Linda Johnstone Mickey Keller Mrs. Michelson
3:45 p. m. - 4:00 p. m.		Break
4:00 p. m. - 5:00 p. m.	United Kingdom, Germany, France & Japan	Mainstreaming: Personal Values (Manual I) Small group discussion

A project of the National Council of the Young Men's Christian Associations of the United States of America. Corporate Body: National Board of Young Men's Christian Associations. A special project of the United States Department of Education, Office of Special Education and Rehabilitative Services, Office of Special Education.

February 1, 1981 - Sunday	ROOM	SESSION
4:00 p. m. - 5:00 p. m.		

Facilitators	Resource
Daryl D. Jenkins, Project MAY	Michael Ballew, Boy Scouts of America
Grace D. Reynolds, Project MAY	Wes Jurey, Boy Scouts of America
Barbara Sanchez, North Texas State	Carrington Mason, Boy Scouts of America
John Sevier, Boy Scouts of America	Randy Routon, Texas Woman's University

6:00 p. m. - 6:30 p. m.	Foyer Area	Reception - No Host
		SESSION II
6:30 p. m. - 8:30 p. m.	Mexico 2	Dinner Guest Speaker - Tools for Mainstreaming Michal Anne Lord, Parks & Recreation

February 2, 1981 - Monday		SESSION III
9:00 a. m. - 10:30 a. m.	France & Japan	Area Resources for You 1. Project DARE Gordon Howard, North Texas State University 2. Project ARTS Randy Routon, Texas Woman's University 3. Agency Resources Michael Ballew, Boy Scouts of America Carrington Mason, Boy Scouts of America
10:30 a. m. - 10:45 a. m.		Break
10:45 a. m. - 12:00 noon	United Kingdom, Germany, France & Japan	Mainstreaming: A Guide to Developing A Program (Manual II) Small group discussion

Facilitators	Resource
Daryl D. Jenkins, Project MAY	Michael Ballew, Boy Scouts of America
Grace D. Reynolds, Project MAY	Wes Jurey, Boy Scouts of America
Barbara Sanchez North Texas State University	Carrington Mason Boy Scouts of America
John Sevier, Boy Scouts of America	Randy Routon, Texas Woman's University

February 2, 1981 - Monday	ROOM	SESSION
12:00 p. m. - 1:45 p. m.	Mexico 2	Luncheon Making it Work With Your Resources Claudine Sherrill, Texas Woman's University
		SESSION IV
2:00 p. m. - 3:00 p. m.	United Kingdom, Germany, France & Japan	Mainstreaming: Your Personal Guide (Manual III) Small group discussion

Facilitators	Resource
Daryl D. Jenkins, Project MAY	Michael Ballew, Boy Scouts of America
Grace D. Reynold, Project MAY	Wes Jurey, Boy Scouts of America
Barbara Sanchez, North Texas State University	Carrington Mason, Boy Scouts of America
John Sevier, Boy Scouts of America	Randy Routon, Texas Woman's University

3:00 p. m. - 3:15 p. m.		Break NOTE: People putting up posters in the United Kingdom, Germany, France & Japan Rooms could do so at this time.
3:15 p. m. - 5:15 p. m.	Mexico 2	Demonstrations
3:15 p. m. - 4:15 p. m.		A. Activities for the Developmentally Disabled Participant - Youth participation Jackie Vaughan, Texas Woman's University
4:15 p. m. - 5:15 p. m.		B. Sports Programs Opportunities Wayne Pound, Lighthouse - Tarrant County Association for the Blind
5:15 p. m. - 7:15 p. m.	United Kingdom, Germany, France & Japan	Poster Sharing Social Linda Barnes, Texas Woman's University You don't want to miss this opportunity to socialize and share program ideas from many groups

DINNER ON YOUR OWN

February 3, 1981 - Tuesday	ROOM	SESSION
		SESSION V
		Concurrent Sessions
8:30 a.m. - 9:50 a. m.	France	1. Aquatics Grace D. Reynolds, Project MAY
	Japan	2. Youth Club and Group Work John Sevier, Boy Scouts of America
9:50 a.m. - 10:00 a. m.		Break
		Concurrent Sessions
10:00 a.m. - 11:30 a. m.	France	1. Camp Programming Marsha Reid, Texas Woman's University
	Japan	2. Community Programming Linda Barnes, Texas Woman's University
12:00 noon - 2:00 p. m.	Mexico 2	Luncheon Quo Vadis Wrap Up

TOOLS FOR MAINSTREAMING

by

Michal Anne Lurd
Parks and Recreation
Austin, Texas

What is recreation? I see it as a necessary part of human development that enables an individual to explore their full potential through a variety of activities.

Now, think back to when you were a child or, if you have children, think back to when they were 3, 4, 5, 6, maybe 7. An able-bodied child spent most of his free time in play, generally simple play. It involved some form of physical activity - running, hopping or jumping. It involved physical achievement - I learned to ride that bike, I was able to jump three feet. It might involve some kind of competition whether it is baseball, football, kick-the-can or whatever and/or it involves sports, physically oriented play. Play offers an opportunity for children to learn important skills such as socialization, the whole idea of getting along with your neighbor, being able to play an entire whatever. It offers the opportunity for peer interaction. Someone has to decide who is going to bring the ball to play, or "yeah, well all right, I'll let you play with my ball", whatever the peer interaction is. Play affords the opportunity for learning of group dynamics and leadership; when you think about children, there is always a leader who emerges.

Play also affords the opportunity for self esteem. "I did learn how to ride that bike, all by myself, no training wheels." A sense of fulfillment, of accomplishment and many other skills are necessary for daily living. The majority of what you are today was learned through play. You may not realize that, but I think if you really think far back or if you watch children today, that is what is happening. Recreation is a human experience which allows us to say who we are. If you think about that, everything you do in your free time really does talk about who you are, what kind of personality. I enjoy camping, and that doesn't necessarily mean that I am an outdoors type, but I do enjoy doing that. Someone who reads a great deal as my mother does, are bookish - maybe, maybe not. If you like to sew or paint or something like that, people say that person is really creative.

Our leisure does dictate our personality. We do use our leisure to say who we are. It is a means of self expression by recreating; and recreating for both the able-bodied person and the disabled-bodied person. That is the premise we want to talk about and that is what this whole conference is about. It is a human experience that everyone, whether they are disabled or able-bodied, needs and can enjoy.

Tools for Mainstreaming

One more definition we need to talk about is mainstreaming. You probably have heard many different definitions. I want to address one that combines everything and says what I look at in terms of mainstream. Normally, or in most cases, we think of mainstreaming in an educational setting. That is where it all got started and mainstreaming is generally thought of as having disabled and non-disabled children in the same classroom for educational purposes. In recreation, I believe mainstreaming is a process of physically and socially integrating handicapped individuals with their peers in activities within the most appropriate environment. You notice I use appropriate as opposed to least restrictive environment. It is the process of moving the handicapped individual from directed to self-directed use of leisure time. It is a physical and social integration of handicapped and non-handicapped and while moving the disabled person from directed to self-directed use of leisure time. That's what mainstreaming is in terms of recreation. The pursuit of leisure through recreational activities is the basic need of the mainstream of society. I think we will all agree to that. It is also a basic community service provided to the mainstream of society and that is why you are here, so that you can broaden that scope. However, to meet the needs and desires of the disabled with respect to recreation and leisure, community programs should allow the individual to learn appropriate behaviors in leisure settings. It is not only about how to play ball, but includes behaviors as well. Remember we said that the able-bodied child learns all these skills in play. Many disabled children are never given that chance to play so they do not develop many of those behaviors and skills so we have to address these behaviors when we are talking about mainstreaming. Such programs should also provide opportunities for individuals to practice their skills of interaction through participation in a variety of recreational activities. Often we sort of say, "Here, this is how you play ball, this is how you swim," but then we never give them a chance to practice that in the real world.

To make mainstreaming work, a fundamental theme of human differences must be accepted and applied and I am going to borrow some words from a gentleman. His name is James Paul and he wrote with several other authors a book called *Mainstreaming, a Practical Guide*. They happen to be educators, but I think their philosophy is in the right line. "Respecting human differences goes far beyond merely tolerating or accepting differences. When differences are accepted, no two individuals are seen as exactly alike. Within every setting individuals differ along the dimension of achievement, intellectual ability, coordination, creativity, leadership, sociability. The attitude of respect for human differences places *value* on individuality, on the recognition of individual strengths and weaknesses and on the development of personal relationships in which differences are valued."

Think about it, some of us in this room are probably disabled. In most, the disability is not visible. We are not sitting in a wheel chair, or have a cane or seeing eye dog or hearing aid or whatever. If you think about the non-disabled population, all of us are different when it comes right down to it. When we can respect those differences, is it any different than respecting the differences of a disabled person who might have that wheel chair, or might have that cane, or that hearing aid, or whatever the case may be. It is a question of respect. Now, I have laid the foundation, philosophically speaking, so let us get down to the tools for mainstreaming.

Tools for Mainstreaming

Let us see how recreation mainstreaming can be actualized, how it can really be put into practice. "Terrific, you have me aware and I am all excited. How do I go about doing all of this?" Recreation mainstreaming can be actualized through a series of support systems and components which are necessary for providing opportunities for normalization. What I want to do for the rest of the time is look at these tools for mainstreaming. I divide them up into three support systems. There are program supports, physical supports, and people supports. Within each of these support systems there are a series of components, functions, goals - whatever you want to call them, that we as professionals committed to mainstreaming need to seek after and accomplish, if in fact, we are going to mainstream activities for youth. So let us look at these program supports and what is entailed in that support system.

First of all, I think you have to look at the whole idea of individualization. Somebody's going to say, "Individualization. That is going to cost me a pretty penny to plan for every person that goes through the Y." I am not saying that totally. What I am saying is that you need to be aware of and meet, or at least attempt to meet, the individual needs, interests, and desires. That doesn't mean you have to go plan a little activity for Johnny over here just because he is in a wheel chair. He can play ball with the rest of them, but you have to be aware of his specific needs. He can not run, but what can he do? He can wheel, but he doesn't have enough use of his arms. Tony will push him. He wants to play ball - that's neat, that's an interest, that's desire. Be aware of individual needs, desires and interests. Also, I think that individualization goes to the point that if we are going to do swimming, not everyone has to swim with the Australian crawl. I am not a swimmer, but some of you may be. If Johnny has to swim floating on his back and doing it this way with one arm, that's all right. That's individualized for his needs, but he is still swimming with everybody. Do you understand what I am saying when I say individualized?

The second factor in terms of the program supports is a need to focus on the strengths and the abilities of the individual, not on the disability. So often we, as a society, look at that wheel chair first and not the person. We think about a handicapped individual. Handicapped is an adjective, it describes that individual, but the noun is the individual. We should look at that person who just happens to be sitting in a wheel chair. I happen to wear glasses and am wearing a blue blazer and have a bum knee. Those are my descriptions, not my abilities. We try to focus on the abilities and strengths of the person sitting in the wheel chair and try to maximize those and not his disability. We ask, "What can he do" rather than "What can't he do?" He can't walk, what does it matter? He can swim, he can throw a ball, he can do other things.

The third thing is that we need to incorporate or try to plan progressive or developmental recreation experiences. What does that mean? You can not expect someone to play baseball if they do not know what a bat and ball are. You can't expect someone to play baseball if they have never thrown a ball. There are many people who have never done that so we have to start at wherever an individual is and work to progress him developmentally and progressively to his ultimate potential. Often when we think "Mainstream" we think it is either black or it is white. Most of the time it is gray.

The fourth thing is that we need to make sure that we offer skill development and the opportunity to practice this skill. If we teach someone to bowl or teach someone to swim or whatever the case might be, if we don't allow them the opportunity to really practice those skills we have taught them, what is the use of doing it? They are not really being able to put those in practice in society then. So we can't just say, "Here, learn this skill", and then forget about it. We have to give them that chance to actualize it in society. Along with that comes the need to provide opportunities to exercise choice of activities. Those of us who are in therapeutic recreation probably are really at fault for not giving the special populations an opportunity to make choices. It is very easy to do everything for them. I mean, that's our job. We are going to take care of them. We are going to plan this recreation program. We are going to provide this. They are going to have fun. If we gave them the opportunity to choose and direct themselves, we would be out of our jobs. If they can't choose what they want to do in their leisure time, have we really begun to reach normalization? Isn't that one of the things we treasure the most, we choose what we want to do in our free time? "I don't want to do anything." That is your choice, no one is telling us that we will not do anything right now. If you think about this, that's the essence of our independency.

The fifth thing is the quality of recreational opportunity. What does that mean? I think it is really fine to say "Our programs are open to the disabled. We'll mainstream, this is super", but if we don't provide them equal equality in terms of facilities, or programs, or personnel, what does that mean? We can't say "We provide services for the handicapped" and give them second rate stuff. That is not equality. I think a perfect example is "We are going to offer swimming for the disabled." Swimming is offered for everybody else all over the city, but the disabled have to come to this one pool to swim. That's not really equality. That means they have to bus all over the place. In some cases that is all we can do because of accessibility and that is understandable, but the goals should be the same as whatever John Q. Public has; since the disabled are a part of John Q. Public, they should also have the same opportunities. Equality of recreational opportunities is necessary. I don't know how many of you do high risk programming, canoeing, horseback riding, whatever; now these are hard ones to let a handicapped person do. They might hurt themselves. We might hurt ourselves too. That is where it really gets down to the equality issue. If I have the right to take risks, a disabled person equally has that right and that is what I mean when I talk about equality of recreation opportunity.

It is good if you have all these programs and you plan to be individualized and you plan to focus on the strengths and weaknesses, but if you haven't discovered the handicapped and where they are, what good is it to have a program? Therefore, we need a recruitment method and identification of the handicapped. We have to be able to find them, identify them, bring them into our program. That may be the hardest thing we have to do. I can learn how to work with the disabled, how to push a wheel chair and guide a blind person, but no one really teaches me how to identify them, how to recruit them. That is very important.

Leisure education is particularly important. Basically, leisure education boils down to about four different facts:

1. It is the actual skill development, teaching how to bowl or whatever.

2. It is community resource awareness. Once we have taught disabled individuals how to bowl, we have to teach them where to go to bowl, when they can go, what it costs, is it seasonal, do you go alone or in groups? We take too many of these things for granted.

3. It entails socialization, just being out in the public and knowing what to do. Once again, most of this we have learned through observation, but a disabled person has not had that opportunity.

4. It is developing leisure values or attitudes. Leisure is important. Leisure is a basic need and does contribute to the quality of life. Now we probably need to do that with everybody in this room. Being a recreator, I am one of the worst to recreate. Even though I know it is important, I haven't made application to my own life so value and attitude is something we need to do with everyone, not just the disabled.

The part that pulls all these pieces together is called the continuum of services. That means having something for everyone at all functioning levels. An earlier session talked about having very specialized, segregated programs where we really teach some skills and address some specific needs; that's one end of the spectrum. Then you get out here on the other end and you have a fully integrated program where John Doe, who happens to be in a wheel chair, says, "I'm going to go take that karate class over there", and does. But not everybody can start at the integrated end. They are not ready, they are not skilled. If they go now, they are going to fail and they may never ever recreate again. That is frightening! Somewhere in this continuum is a place for them to begin and we have to know where and advise and eventually work them up through the continuum. There are those that might start in the middle and never ever get to that integrated experience, but nevertheless, they are still having their needs met and their rights met in terms of having recreational services.

Last, but not least in terms of program support, is that we need to provide a sense of achievement, fulfillment and satisfaction and fun, hopefully to the highest level and hopefully in the most appropriate environment. If we don't feel good about what we do in our free time, if we aren't meeting some basic needs and satisfying them, if we are not having any fun, we do not have the motivation to come back and recreate that activity. This is the whole crux of recreation. Think about what we do. I don't like to play tennis, that's nothing against tennis, but I find it boring; probably because I can't play it well. I receive no sense of fulfillment, satisfaction, or fun when it comes to tennis and I'm not going to do it again. All of us experience that sense of feeling, all of us have that need and so do the disabled.

Let us look at that second support system which is probably the real nitty gritty if we are administrators - accessibility, transportation and funds. If we are to provide a mainstreaming program, we do need to address these areas. We have to have a facility that is accessible to the handicapped or at least a plan in mind to remove some of those barriers. It may be simply a ramp to the front door, maybe a couple of rails in one of the stalls in the bathroom, maybe a portable lift swing in the swimming pool. Maybe the facility is such we can't afford to adapt it so we have to look for alternatives, but first we must try to make that effort physically to make the facilities accessible. It's great when we have our program geared to accept the handicapped and mainstream them, but if we can't get them into the place where the program is, what can we do? We can move the program to another place. Sometimes we are just short of places.

That brings up another part of that physical support system which is transportation. Transportation is probably the number one barrier to leisure activities for the disabled. We know someone will say, "It is because I can't get in." That's not it. We have too many laws going for us now so that most places are becoming more and more accessible. It really is a question of getting there. It is great for us to say, "We have a program that's open, a building that's accessible, you can come on in"; but if they can't get there because they don't have the support system - mommy or daddy or the bus to transport them, it is no good. Whether or not we should provide transportation is an expensive issue to address, but it certainly is a barrier we must address with our eyes open because it will affect our program. If we can't afford to transport the people, it will affect our mainstreaming efforts. That doesn't mean that the mainstreaming efforts will fail, but if we were expecting twenty-five people in the mainstreaming program and only five come, transportation may well be the problem. If you are working with institutions or agencies, often they have their own transportation which helps some of your problems, but transportation will probably be the largest and biggest barrier to overcome.

The third part of physical supports is funding - the dollars. The biggest excuse for not mainstreaming is, "Well, it's going to cost me money and we just don't have money in the budget to mainstream." Yes and no. There are many ways to practice mainstreaming components and techniques without having to call up the dollars. There will have to be a financial commitment, if for no other reason, the additional staff, but we can always use volunteers. Transportation can, perhaps, come from volunteers or in cooperation with another agency. Some financial commitment is probably necessary. We are not talking megabucks necessarily so we should not let our administrators use this for an excuse for not having the program.

People support is the last support system and probably one of the most important support systems in terms of mainstreaming activities for youth. Probably the number one thing, and I am biased, is a qualified staff because the staff people make the difference in any activity. For a group of nondisabled people, the staff person is the model, the role model, arbitrator, whatever is needed. We must have qualified staff for the disabled as well. However, I know that often it is not logistically possible in terms of budgets and other restraints. I would certainly ask that those in hiring positions hire a qualified person if that means a degree in therapeutic recreation or recreation. We can find many, many capable people to do the job. I think the key is their sensitivity, their awareness, their honesty in dealing with people, their respect of their fellow man. We can train them how to push a wheel chair or guide a blind person or even sign to a deaf person, but we cannot teach that sensitivity. That is inborn, that is there. We can highlight it and bring it out, but we can't teach it. And if hiring a therapeutic recreation person or a recreation professional is not possible, I would urge consideration of a consultant, at least on a part-time basis, to at least train the staff. It will give the staff a head start on the mainstreaming process. Along with the staff and because we are working with folks with special needs, there will be a need for more leader-to-participant ratio in many of the activities. This will vary with the activities. We may not have enough budget-wise to hire three more staff because we are going to have nine disabled children in your program. Remember there are volunteers and I am sure many of us represent organizations that depend heavily on volunteers. I would also urge us, as a third component of this support system, to provide ongoing and inservice training to staff, volunteers, and even to the parents of the participants. Why parents of participants? Many of the disabled children's parents need to know that there is an area of acceptance; that recreation is something important for their child, it can be fun, it can be beneficial. Many feel that Johnny can't do that, he is in a wheel chair. And maybe it is because society has never said, "We expect Johnny to play," or "We know he can." They need to be educated that this opportunity exists. There may be a need to educate parents of non-disabled children and say, "You can't catch this. It doesn't rub off." The inservice training must address all facets of personnel in the program.

The fourth thing that I would suggest is that we provide opportunities for the handicapped individuals to either work as staff or volunteers in our programs. Who are our leaders? They are the role models for our non-disabled children. Well, if a disabled child can get some role modeling from a non-disabled person, think how much more role modeling they can get from a disabled leader. If we have never been in a wheel chair, we cannot truly sympathize with someone in a wheel chair. Having always seen the sunrise, we cannot understand the need of a blind child to say, "What is it, tell me what it looks like?"

Last in terms of people support, which probably wraps up everything, is what I call public education. Public education is needed that will promote community acceptance, that will solicit citizen input, and that will provide visibility of the handicapped. We, as professionals, are providing activities and services to our communities. If we are smart, we will plan with our community, not for them. That is especially so with the disabled. We should seek input from the disabled community. If we have not created some kind of atmosphere of acceptance and of understanding, no matter how well our staff is ready and prepared; if we haven't somehow prepared the other members of our organization and our community for acceptance, mainstreaming will be harder to achieve. In the past, we put the disabled person in the closet or hid them in the background. This is not so any more. Disabled persons are standing up and saying, "We are members of this society, we have rights, we have needs, and we are going to get them." They are no longer the silent minority, but are becoming vocal. They will help us to achieve much of what we need and want to achieve through mainstreaming. We should not be ashamed of having them in our programs. They will provide us with that visibility. At the same time, we should not parade them around and make a spectacle of them either, "Oh look at us, aren't we good; look, we have six wheel chairs, three blind and two deaf mutes in the back." We do not want to do that either.

The concept of mainstreaming sounds very philosophical, very expensive and it will take a great deal of time, but we can do it. Perhaps what has been presented is Utopian and idealistic in terms of tools for mainstreaming, but if we make plans which will consider everyone of these components and work toward them, we are beginning to mainstream. Bit if we sit back and say, "It's too much to do", we will never make it. These are critical factors and components to truly achieving mainstreaming of activities for all ages, all disabilities, all walks of life, all ethnic groups, and all social groups, not just the disabled.

If I were to summarize for you, I would say that mainstreaming activities for youth are possible and can be successful if there are three basic things:

1. If there is a sense of awareness and attitude of respect and acceptance,

2. If there is a focus on individual strengths and abilities, progressive and developmental experiences and equal opportunities, and,

3. If there is a commitment of time, space, personnel and funds,

then mainstreaming can be successful.

I guess I would say that the process of moving a handicapped individual from directed-use, where we tell him what he is going to do, when, and how much, and what is right and what is wrong, to the point of self-directed, where he says, "I'm going to do this today for this long and with these people and this way, that mainstreaming, is similar to the game of chess. In a chess game it is impossible to play until the players can identify each chess piece and know what each can do. We cannot mainstream until we identify our people, until we assess what they can do and know what we can do and how we can do it together. So my challenge is that we each consider the mainstreaming project, perhaps like a chess game, make that commitment, and we will be successful.

Question: Tell us about the Arts Program.

Michal Anne Lord: Our Arts Program has been exceedingly well received. We received a grant through the National Committee on Arts for the Handicapped and basically, it is an opportunity to expose disabled individuals; predominantly youngsters, but also adults, to the various art forms. We do dance, drama, photography, macrame, pottery, the whole gamit. Disabled individuals come to a one-day or two-day festival where it is a "hands on experience", taste and touch things. We also have invited, up until this point, strictly integrated classes in school which are already supposedly mainstreaming, but maybe there is not total acceptance. They come and they say, "I didn't know Johnny could do so and so." That has been extremely successful. From that we have taken ongoing arts programs back into the schools and have taken the entire school or part of the school, handicapped and non-handicapped and had more art experiences and showed how we can use the arts as a part of the whole learning process of academic work, etc. Don't think mainstreaming always has to be done through the front door. "We'll take this handicapped person and put him in this class with all these non-disabled people." That's the front door integration.

I would suggest the use of the back door. I find it much more productive and much more successful. By back door I mean we plan activities that will meet the individual needs and will focus on the strengths and abilities of the disabled person and then we say, "John Q. Public, you are not handicapped, but would you like to join us in this? Well, come on." They join up and perhaps they are in the smaller ratio and the disabled are in the higher ratio. What we have done is we have guaranteed that each individual's need is met and that, hopefully, there is a sense of security and trust on the disabled person's part in terms of leadership. Our leadership is sensitive to their needs and sensitive to the needs and curiosity of the non-disabled as well. It is very much the mixing of non-handicapped and handicapped in a recreation experience which is designed from the disabled point of view as opposed to the non-disabled. We have found that this is a much more effective way to achieve mainstreaming. It is probably a back-door policy, but I call it "buddying up", a buddy system where we do a one on one. This is a system where half the group is handicapped and half is non-handicapped. I think scouting has used it and that works very well. We have our integration factor, properly planned program for the disabled side of the family, but we still have that interaction and cooperation in terms of the other group.

MAKING IT WORK WITH YOUR RESOURCES

by

Claudine Sherrill
Texas Women's University

On Being Different

Watching without sight,
Running without legs,
Conversing without voice,
Loving without prejudice,
Oftimes it is belief that makes it happen . . .
    What's the difference in being different?

Acts which are naive, those deemed grand,
Small, tall, some with, some without,
Some who can, some who can't . . .
    What's the difference in being different?

Thinking, feeling, acting, sharing,
Moving, gaming, loving, romping,
You and I, not the same but
Yet the same because we are by fate just people . . .
    What's the difference in being different?

Oh for the chance to share my dreams,
To hold hands, to join in happiness,
To play your games, to taste the differences in life,
And not be scorned and turned away . . .
    What's the difference in being different?

-Dave Compton
Leisurability 2 (July 1975): 27.

This poem eloquently states the rationale for extending the recreation and leisure services of youth agencies to all persons regardless of individual differences. What is it that enables us to conceptualize abilities and assets in handicapped persons, rather than disabilities and liabilities? What, in a Y or the Scouts or a church group, makes the difference to the youth of the community who are labelled as "different"?

The difference is in resources: the staff members and volunteers who deliver the services, the facilities and equipment, and of course the budget - both present and future. PROJECT MAY strongly supports the importance of resources in "making a difference" in the second of it's mainstreaming books, A Guide to Developing a Program (Reynolds, 1980). In it we are led through a planning/program development model in which we first clarify goals in relation to mainstreaming and then identify our resources for achieving such goals. The guide discusses three kinds of resources: (a) human, (b) physical, and (c) financial. I shall focus only on the first of these for I believe that human beings are the only resource needed to make mainstreaming work.

The Significance of Human Beings

Only human beings are significant. Persons with conviction, courage, and creativity ... persons who dream dreams like George Bernard Shaw, and later Robert Kennedy, who said, "Some men see things as they are and say, why? I dream things that never were and say, why not?" Men like Martin Luther King who actualize their dreams, whose thoughts and words motivate change; women, like Laureen Summers, who stated:

> "I am a weaver with ... cerebral palsy. People like myself need to feel expectation and appreciation from others - that we all have good potential and the ability to be cooperative and productive... Weaving has gained me support and respect in a world which I am sometimes afraid to enter... Art (recreation) is an individual statement; it opens the door to an understanding which has not been there before. It is a way to reach beyond the fear that separates us from each other. It has the potential to bring us all together at last."

The human resources that make mainstreaming work are able bodied and disabled, healthy and chronically ill, intellectually bright and mentally retarded. We have the whole spectrum of individual differences from which to draw talent, dedication, and commitment. All that is needed is one person in each youth serving agency to step forward and lead.

Mainstreaming has its roots in humanism (Sherrill, 1981). It is a part of the great American dream. It is integration rather than segregation ... it is an assertive celebration of individual differences ... the caring for and prizing of all of our resources, helping each person to become all that he or she can be. In so doing, mainstreaming enables its facilitators to become more human, more real, more alive ...

What trait or personal characteristic is most important in making mainstreaming work? Researchers tell us it is not knowledge about the handicapped or even experience; rather they suggest that we identify our staff members who have the best self concepts, who are secure within themselves and thus not fearful of the unknown or the different. Combs et al. (1971) states in this regard:

> "Persons with high self-esteem, able to accept themselves, are also able to accept other people; this makes effective interaction with others much more likely. Because they believe in and trust themselves, they can act with high degrees of autonomy. They are freewheelers and able to move off in new directions, which is what is meant by creativity. People open to new experience enjoy exploring ... (p. 156).

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Finding and Involving the Handicapped

What else is essential in the initiation or facilitation of mainstreaming within an agency? Finding the handicapped! Research shows that loneliness, alienation, and transportation problems act as major barriers in recreation participation for the handicapped, Noe (1977). Typically leisure education has not been included in the schooling of the handicapped. They may not even know your agency exists ... or they may have no friends to come with. How many of us go alone to a ballgame or out to eat or even to a friend's house? American society functions in pairs; we each try to have at least one friend.

Research shows this to be a major problem among the handicapped. Stanfield (1973) in a study of 120 graduates of special education programs, ages 19-21, found that only 23% felt they had friends they could go visit and only 60% had sufficient skills to travel about their community alone. Katz and Yekutiel (1974) interviewed parents of 178 retarded adults. The most often reported type of leisure activity was watching television and listening to the radio. Only 22% indicated that they had friends and engaged in social interaction outside the family. Ervin (1980) interviewed 30 blind persons, ages 16-50, to learn their opinions about physical education and recreation in their present lives as well as in childhood. Most of her subjects expressed negative feelings about their past and present involvement and/or inclusion in family, neighborhood, community, and church recreation. When asked, for instance, does your community offer recreation programs and do you take part, 47% indicated that they had no knowledge of such programs. Illustrative of the kind of response elicited was the following by a 32-year-old male:

> "Well, I'm not aware of what they are, so I don't take part in them. I kind of wish they would let us know, but I don't want the activities to be just for the blind. I've got a bad feeling about getting all of the handicapped people together in the community. I think you ought to get the handicapped into the community with the sighted." (p. 96).

How then do we find the handicapped so that mainstreaming can be begun? How do we convince them to try something new? To come to an unknown center, to meet and interact with the able bodied ... to risk stares and possible rejection ... to experience the discomfort of feeling that you are making others uncomfortable.

The best resources in solving these problems seem to be the families of the handicapped and, of course, the handicapped themselves depending upon the degree of involvement. Mainstreaming family recreation seems to be a logical first step toward integration of individuals. A progression might be followed in which first the entire family is involved in some events, then part of the family, then perhaps only a sibling and the handicapped person, until at last he or she feels confident enough to come alone. Incidentally, this approach may lend confidence to staff also who may need assistance, for instance, in understanding the speech of a cerebral palsied person or in learning to manipulate braces and wheelchairs.

Making It Work With Your Resources

Involvement must begin at the planning level rather than with publicity of an already planned event with encouragement to come on out and participate. Home visits constitute an excellent first step in mainstreaming. Parents often have a difficult time finding sitters for severely involved handicapped family members, hence, why not go to the parents? Why not use the mobile van concept and carry games and recreation activities with you for that first home visit, establishing rapport through playing together rather than just talking? Like "meals on wheels", games on wheels offer as much in socialization as in the nurture of other needs. They build up confidence of handicapped persons and prepare them for leaving the house and coming to the agency.

Employment of Handicapped As Resources

The employment of handicapped persons as staff members in youth serving agencies and recreation centers can be a major contributing factor to the success of mainstreaming. Research (Comer & Piliavin, 1972) shows that physically disabled persons react differently to the nondisabled than to confederates perceived as similar to themselves. For example, significant differences were found to favor interviewers simulating disability. "With the interviewer without impairments the subject with physical disabilities responded by terminating the interaction sooner ... displaying greater motor inhibition ... exhibiting fewer smiles ... demonstrating less eye contact ... and tended to feel less comfortable during the interaction." (Comer & Piliavin cited in Schroedel, p. 77). Research (Donaldson, 1980) indicates that direct contact with handicapped persons is the most effective way to change the beliefs and attitudes of nondisabled persons; thus the best way to inservice staff members for mainstreaming appears to be the use of a disabled person of equal status. Donaldson defines equal status relationships as "those in which the handicapped individual is of approximately the same age as the nondisabled person and/or is approximately equal in social, educational and vocational status (p. 505). It is essential also that the handicapped person not act in a stereotypic manner. He or she must be able to talk comfortably and unemotionally about problems.

The handicapped, whenever possible as salaried staff members (not volunteers), should have the right to be resources for mainstreaming. The "token" handicapped worker in an agency or center is a powerful force. Take, for example, the first such token staff member I employed as a graduate assistant at the Texas Woman's University. Don was a Vietnam veteran, a double leg amputee, and an outstanding wheelchair athlete. Our campus at that time was an architectural challenge even for the able bodied, it had no ramps and no curb cuts. Moreover no one had ever noted the need to increase accessibility. Don attracted a great deal of attention in his wheelchair maneuvers about campus. He was colorful in his actions and open in his communications. I'll never forget the day that he couldn't get his wheelchair up the long flight of steps into registration. In disgust he hurled the chair into space and "stumped" it up the stairs. At just that moment the president of the University was also ascending the steps. A very dignified, caring, and supportive lady, she was obviously quite dismayed. That day marked the beginning of the removal of architectural barriers on our campus. Not only was Don instrumental in creating attitude change, but he also had the contacts in the state capitol to get the university matching funds for barriers removal. A human resource thus can also be a financial resource. In fund raising to facilitate mainstreaming activities, handicapped persons are generally much more persuasive than the non-handicapped.

Since Don, I have tried to maintain a one-to-ten ratio of handicapped to non-handicapped on my staff. Since my staff is small, this commitment results in the employment of one person each year as our "token" handicapped. This arrangement necessitates flexibility in work assignments and reinforces the concept of utilizing abilities while covering for one another's disabilities. Even among seasoned mainstream workers it promotes new understandings and appreciations. Few of us, we realize, have ever worked and played with the handicapped in "equal status relationships." When the staff (or leaders) in an agency achieve this state, the youth we serve have models to emulate. Our actions in regard to mainstreaming really do speak louder than our words.

Another reason for utilizing the handicapped as employees rather than volunteers is the need to model for other prospective employers as they consider integrating their staffs. The U.S. Census statistics (Razeghi and Davis, 1979) indicated that 85% of the disabled have annual incomes of less than $7,000. Of these persons, 52% make less than $2,000 a year. If our budgets are inadequate to offer full time jobs, then the handicapped can be employed on an hourly basis or for a lump sum under the consultant category. Mainstreaming should be a team effort between the handicapped and the non-handicapped, not another endeavor in which we struggle for additional resources so as to extend services to a needy population. Handicapped persons want to help themselves and others. Often we prevent their doing this by conceptualizing them only as clients or participants rather than as leaders and presentors.

Networking in Resource Identification and Utilization

Another successful approach to finding resources for mainstreaming is networking. This entails forming cooperative, supportive relationships between your youth serving agency and already established advocacy groups like the Association for Retarded Citizens, Easter Seals, the American Lung Association, and Mayors' Committees on Employment of the Handicapped. In this way you can have available a network of resources, often exchanged without charge. Networking is not easy. It means giving a great deal of yourself and motivating your staff to do likewise ... joining new organizations, attending their meetings, serving on their committees, and working toward priorities which may not be foremost in your own value system. Networking is, however, a reciprocal process. We help others in areas like employment, transportation, and housing. In return, they advocate for our agencies and for quality recreation and leisure education services. Carl Rogers, the well know psychotherapist, beautifully summarizes the importance of reciprocal work in the mainstream effort. He states, "In my judgement the warm, subjective, human encounter of two persons is more effective in facilitating change than the most precise art or technique growing out of learning theory or operant conditioning" (cited by Buscaglia, p. 287).

Resources in Relation To The IEP Process

Perhaps the most important resource for mainstreaming is the special education director in your school district. Public Law 94-142 establishes definitions and processes through which recreation for the handicapped can be funded through school resources. The key is in understanding the concept of related services and the process of individualized educational programming (IEP). Under PL 94-142 recreation is a related service. If we can show that recreation or leisure education is needed to "assist a handicapped child to benefit from special education," we can seek to have this service written into the IEP and funded by the school district. This means that we need to understand the long range goals of special education and to task analyze our program offerings to determine specifically what activities/services we offer that handicapped youth need before they can benefit from traditional school learning. Chief among the services that come to mind are socialization activities, i.e. learning how to behave appropriately in social settings and how to interact with others. Also important are adaptive behaviors for game readiness (Sherrill, 1981, p. 61) like responding to name, following simple directions, staying in one's own space, and learning to imitate or model.

If parents can be made to understand the contributions of recreation and leisure education to special education, they can become powerful resources to our youth serving agencies. PL 94-142 mandates that parents must be involved in the IEP process and must sign the written IEP which subsequently guides their child's education. Parents can refuse to sign the IEP until certain services are agreed upon providing, of course, that the need for the services is documented by valid and reliable assessment. Parents can also instigate legal proceedings if they believe that the terms of the IEP are not being met. Illustrative of the power of parents in this last regard is the record of an IEP hearing (Massachusetts Department of Education, 1980) concerning a 14-year-old girl "with Down's Syndrome, resulting in global developmental delays." Among the substantive issues in the hearing were:

1. Whether the 1979-80 and/or 1980-81 IEP for Sandra T. is adequate and appropriate to meet Sandra's special needs in relation to recreational, extra curricular activities and leisure skills provisions of that plan.
2. Provisions for access to, and equal opportunity to participate in, extracurricular activities in after school hours which are offered to students without handicaps ... (p. 3).

The record of the case included more than 100 pages of documents and 24 hours of testimony. Present at the hearing and no doubt instrumental in it's outcome was Dr. Gerald Fain, Coordinator, Leisure Studies Program, Boston University. As a result of the hearing, the Old Rochester Regional School District was ordered to provide the following:

(a) An after school program of related services for Sandra T. incorporating socialization, recreation, physical development and leisure education objectives for a minimum of six hours per week. Such program may include a small group of other special education students, as appropriate to their needs and development, at the agreement of their parents. The after school portion of the Special Olympics Club should be considered a part of this program. Further, such program should include activities available to non-handicapped students with additional supervision or modification as Sandra's parents, school personnel and a consultant therapeutic recreation specialist deem appropriate.

(b) An aide shall be designated to carry out the program under (a) above, with supervision of a teacher, preferably Mr. McFee.

(c) A therapeutic recreation specialist shall provide a consulting and in-service program to interested teachers, specialists, and the designated teacher aide for a minimum of one hour per week for 15 weeks dealing with topics of therapeutic recreation, physical education, curricular activities, provided that such a program is available to school personnel, without cost to them and within reasonable proximity to the junior high school.

(d) The therapeutic recreation specialist shall provide direct service to Sandra individually or in a small group for a minimum of one hour per week.

(e) Quarterly progress reports shall conform with c. 766 Reg. 337.1 as to review of Sandra's progress in the general and specific objectives of her IEP. (pp. 15-16).

Thus it can be seen that parents, with inservice training to understand their rights and the IEP process, can be valuable resources in making mainstreaming work. PL 94-142 does not specify the setting in which recreation and other related services must occur. Sandy T.'s afterschool program could have been at an agency or community recreation center. The important factor is cooperative parent/agency involvement in ascertaining that recreation is written into the IEP document and thus considered an integral part of the handicapped child's education.

Resources in Government

The effects of PL 94-142 and Section 504 of the Rehabilitation Act on resources for mainstreaming are just beginning to be felt. Unfortunately, this legislation is in severe jeopardy. The Reagan/Stockman proposal for block funding of education, as well as cuts in appropriations, will render the legislative advances of the 1970's meaningless. Now, more than ever before, recreation and agency personnel need to become involved in government, in lobbying and campaigning, and in the education of public officials. We need to visit our congress persons in Washington D.C., maintain periodic telephone contact, and provide continuous letter writing feedback concerning issues affecting the handicapped. The men and women in the Senate and the House of Representatives are our resources; the money they are discussing is, at least in part, our tax dollars. We need to develop the self confidence and assertiveness to use our government resources to make mainstreaming work. Our input, particularly when organized according to networking concepts, does make a difference in voting patterns.

Ourselves As Resources

Finally we, ourselves, are our own best resources for making mainstreaming work. Our involvement will depend, in large part, on the extent that mainstreaming is self actualizing and satisfying ... this in turn relates to being "real" or authentic, in touch with the world as a caring and action-oriented person. What does it mean to be "real"? A children's story, The Velveteen Rabbit, conveys the essence of realness better than I can. In this passage two stuffed toys, a rabbit and the skin horse, are talking:

> "WHAT IS REAL?" asked the Rabbit one day, when they were lying side by side near the nursery fender, before Nana came to tidy the room. "Does it mean having things that buzz inside you and a stick out handle?"
>
> "REAL isn't how you are made," said the Skin Horse. "It's a thing that happens to you. When a child loves you for a long, long time, not just to play with, but REALLY loves you, then you become Real."
>
> "Does it hurt?" asked the Rabbit.
>
> "Sometimes," said the Skin Horse, for he was always truthful. "When you are Real, you don't mind being hurt."
>
> "Does it happen all at once, like being wound up," he asked, "or bit by bit?"
>
> "It doesn't happen all at once," said the Skin Horse. "You become. It takes a long time. That's why it doesn't often happen to people who break easily, or have sharp edges, or who have to be carefully kept. Generally, by the time you are REAL, most of your hair has been loved off, and your eyes drop out and you get loose in the joints and very shabby. But these things don't matter at all, because once you are REAL you can't be ugly, except to people who don't understand ...but once you are REAL you can't become unreal again. It lasts forever."
>
> (Williams, 1971, pp. 16-17)

The mainstreaming mission is not easy ... we sometimes do lose our hair or it turns gray ... and our joints get loose and tired ... we don't have time for shopping and hair styling and we get shabby. But in helping others to find self actualization in the mainstream or their least restrictive environment, we ourselves become more REAL and life is more meaningful. Commitment to mainstreaming is a value system and a life style ... it lasts forever.

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YOUTH CLUB WORK

Panel Discussion

John Sevier: Let us get a little more directive than nondirective. When you came here, did you have one or two leads that you had hoped to accomplish or had been met when you came in?

Participant: We know so little about the subject of mainstreaming that I don't believe we have any questions we know how to ask.

John Sevier: All right

Participant: I'd like a little bit of "how to's", how to set up, different kinds of approaches.

John Sevier: You sir?

Participant: I guess the "how to" bit.

John Sevier: We might say that you are looking for programs to assist you from ideas and concepts and goals of this program. How about you, what did you come here hoping to get?

Participant: 4-H

Participant: Ideas from other agencies, organizations, programs they have been in.

John Sevier: Carrington?

Carrington Mason: Everyone is using volunteers. Everybody needs more volunteers than they have, right?

Participant: That is true.

Participant: That is coming from a volunteer.

John Sevier: That is coming from a volunteer, yes. Carrington is a volunteer and the man to his left is the paid professional in this area. He is executive in charge of handicapped scouting in the Houston Council.

Participant: I was wanting to get information on how to implement different programs.

John Sevier: Do you mean programs that already exist or new programs altogether to supplement what you are doing at the moment?

Participant: I just came along to find out anything I could.

Youth Club Work

John Sevier: Carrington, would you kind of tell us what you have going in your council area with respect to the handicapped?

Carrington: Well, we have a program in which we are attempting to mainstream the handicapped in existing troops, dens, explorer posts. We have all ages to twenty-one and are trying to get the existing organizations to take in more handicapped with those they already have. We also have, going concurrently, the organization of special units for the handicapped. Some of those are in schools where you have a group in wheel chairs in the room. Transportation is a problem. You can't get them together in the evening for a meeting or on Saturday so the school district makes class time available during the week to hold a scout meeting. The boys come in uniform, the leader comes in uniform, and they will have that scout meeting on school time.

Another area for special units are the residential institutions, the State Schools for mentally retarded. There is a residence for mentally retarded in connection with the Harris Brown Center in Houston that has quite a troop sponsored by the Association for the Retarded. These are special young people. School districts mainstream as far as possible and we are attempting to do the same thing, but there is still a place for some special units. We simply adopt or adapt the scout program where necessary for the handicapped, following the regular program just as closely as possible, maybe as ingeniously as possible.

John Sevier: Would you care to speak about what changes have been made?

Carrington: For the mentally retarded, it usually takes a long time to go from tenderfoot to second class. A boy can get discouraged. This program gives him an additional twelve tidy packages hardly bigger than your thumbnail. As he passes various points of progress on his road, he gets these little recognitions. It gets back to the instant recognition proposition. The whole purpose of this thing is not to let him become discouraged along the way because it may take him two or three times as long as it does the non-handicapped boy to get to the same place. You modify requirements. Instead of having to repeat the scout oath alone, he may be permitted to repeat it with others. He learns it when he has the reinforcement of others. It makes it a little easier for him to come through with this particular accomplishment.

John Sevier: Those of you who came here with **programatic needs to be settled** might gain one here. You might think in terms of adjusting your present program with the rewards associated with the growth of the youngster in your program and the recognition by allowing more time and by dividing your progress down into smaller steps. Each step is then achievable in a short period of time within the recognition attached to it. This can be done in the 4-H Program or even in the Girl Scout Program. I know more about the Boy Scout Program than anything else because I represent the Boy Scouts. In essence, the rules for advancement have been adjusted to allow more time, either for slowness of physical advance or slowness because of a mental impairment.

Youth Club Work

Carrington: The use of beads or arrow points for Cub Scouts is an example where you are doing this. Because of lack of maturity at that time, the award needs to come more quickly and frequently. When the boy gets older, he is able to wait a little longer.

John Sevier: What about those developmentally disabled? They function at the top level mentally so do you use the Cub method on a Scout who is 18 or 20 years of age? You don't modify the rules, you modify the method of doing the job.

Dan James: I wanted to tell you about the 4-H Program. Currently it is not unusual for 4-H programs to work with Scouting programs using their recreation and resources, particularly in the high school age programs. It is not done very often any more. It used to be done more so in the past than it is done now. That is another resource that can be used.

Participant: I was wondering if we need special training for volunteers to work with those needs. How do you recruit them? Where do they come from and what do you do next?

Carrington: The two principal sources, I would say, are parents of handicapped and people who are already involved with agencies, working with agencies, working with the handicapped. The other problem is to get those who are working with the scouting program to know the scout side and teach them a little bit about working with the handicapped. Frankly, the problem there is to get them over that fear. They are afraid of the handicapped or that they might do something wrong.

John Sevier: They tell us that they break, that when you work with a person with cerebral palsy, you do not dare pick them up or do anything else like that because that would upset them. Of course, that is foolish. People with cerebral palsy shake a little bit, but they do not break when they fall down.

How about the Girl Scouts? Do you want to comment a bit on what you are doing to reach out to the handicapped so maybe we can provide a guide for the others.

Girl Scouts: We have reached out, so far, to the mentally retarded in school and in public school systems. It is totally for mentally retarded children so it is not as though they are mainstreamed into school in our area. We are trying to get through to principals of other schools in Ft. Worth and in our four-county area who have had similar situations so that we can begin the same program there. The problem is trying to convince the directors and the principals that it would work because it is the same thing; no after school, no before school, no during school. You are going to fail, but please try. That is the kind of attitude we really have a hard time with because other groups have come in and tried to provide this and have failed. They just get their hopes up and everybody is unhappy. We have a very good success story going and we are trying to move it into other areas.

Participant: Can I ask a question? I think the biggest thing that you and I will find when we go back is that if we make up goals to mainstream and we hope that this will happen; how do you, from your experience with the Boy Scouts, convince a leader who has fifteen normal boys to take a couple more boys with special needs? She will say, "I'm doing fine. Fifteen are all I can handle." You know what she is really saying, "I would take two more, but not those two that you want to give me." I think that will be our biggest problem.

Participant: You could promise them more help sometimes which might give them a little confidence. We can sometimes trap groups into taking handicapped people, but it is very difficult to get them into normal programs. If you are looking for a short term gain, it is going to be tough. We encourage all our handicap units to participate in all other regular activities that we have for everybody else so that people become aware they exist and become aware that their functioning level is probably different from what was expected. People become a little more comfortable around them in a very relaxed setting. Look at the Boy Scouts in a competitive camporee situation. You will see they become more aware of others. We try to promote awareness of others, it's part of the constant awareness. There are always articles about it in the in-house journals. It is a constant thing so that over a period of time, it is very possible to adjust in some attitudes.

Carrington: Scouting gives us a real opportunity for these boys in the special units to have a troop of their own and to put on a display in a scout show and people have a chance to see what they can do. They get exposure.

John Sevier: Speaking to that point, this weekend, pretty much all over the country, is Scouts' anniversary week. Scout troops have been invited to put on displays and let them show their work. One troop in my council every year puts some paneling up on the wall and they rapel down that paneling and let people see that even children can rapel. It is not something that they do just in the paratroopers and places like that; even the handicapped can be trained to rapel. I think the key, as they indicated, is that there should be some kind of a training session going on. As you try in your outreach program to go out and set up units and sell your programs to handicapped kids, you should also run concurrently a training session so when a unit comes into being, the leadership is there ready to take them on. Otherwise you get a unit and no leadership and then it falls apart and the participants'hearts are broken, to say the least.

Participant: Why would we want the special training as long as we get every-day, run-of-the-mill, high quality training, because what staff need to know is how the program is intending to work? We know how our program is intended to work and we go and talk to the

Scout leader and we say the same thing to the next Scout leader and I think that is the most important step; that they understand how the program works. Then we move in with special resources or special adaptations, but there is no way and this is what they will say, "What would Johnny want?" You don't know Johnny and, "How do I work with this group of boys?" You can't tell them that because you haven't met these kids. There is no substitute for the regular training. The first step I like to see is that they get to regular training like everybody else. Then follow this with the resources and aspects of special training, particularly in school units where there is a teacher available as a professional. They are there to help. We do run some specialized training from time to time, but I think most important is the regular training that everybody else gets, the mainstream training that you get, just like everybody else.

Participant: I think the ideal situation is to include special training as a part of the program's regular training, just one section of the regular training so everybody gets it. This works for the present leaders of regular units.

Participant: You begin the long range plan of getting everybody mentally ready. Where do we want to be ten years from now? What are we going to have to do suddenly and consistently, day after day, year after year, to change attitudes? That goes for staff as well.

Girl Scouts: I know from Girl Scouts the thing that also takes a long time is that in order to implement that in your training, that volunteer task group in charge of training has to realize that including special training is an important part of training. If we went in and said, "Include specialized things in your training," they would say, "Well, we don't have any of those children. Why do we need special training for the small percentage we might have?" It will take educating down to even the staff that goes into training. We have to train the trainers to tell the people.

John Sevier: I strongly feel that the Boy Scouts are behind the handicapped at the national level in terms of policy and to some lesser degree because it hasn't reached all the way down into every council and every district. It might be symbolized by the pictures that Norman Rockwell put together for us. It wasn't until the last picture he painted that there was a picture of a handicapped child in them. They were doing it, but didn't publicly acknowledge the fact that they were doing it. It has taken a long time. Don't look forward to making a great leap forward. It is going to have to come in small steps and it is going to have to consist of efforts to make the public aware that you are willing to accept these children into your program. There has been no public statement made to that effect, but it has happened here and has happened there.

Youth Club Work

How about 4-H? Is there anything that you do with your program to facilitate the entry of handicapped into it or is it a case of you now trying to come into this field?

Dan James: Most of it has been isolated cases for professional staff and the county and work with schools. They have provided the 4-H program to them. I mentioned yesterday the horse project and there are many clothing, foods and nutrition programs. One that has probably been the most successful in Denton State School has been consumer education. It teaches handicapped young people something about money, how it works, how to handle it. Students go on shopping trips and maybe we see quite a bit of recognition in that setting up there with the family of handicapped to encourage them. There is really more of an isolated case where the professional staff member that has an interest in them or even an awareness that might be with a volunteer who will do some listening. I would say that one of the largest things is the awareness of the professional staff to take an affirmative action on it.

John Sevier: I know the Boy Scouts program works well enough, but at times it is going to take conflict with 4-H. 4-H is one out. The old Ford School is one of several segregated schools dealing with the orthopedically impaired and the old Ford School had a Cub pack for awhile and then adopted the 4-H program. While visiting there I could see the program has worked very well. About sixty orthopedically impaired young people go to the Old Ford School. They are transported there in the morning by bus system and transported home so that whatever happens has to happen during school hours. It can't happen after school hours; otherwise you miss your bus and then how do you get home? We have that continual problem.

Now, how about your park program that you were working with? Have you opened it to the handicapped and do you have problems trying to meet their needs?

Park Program: No, my situation is a little different. Basically I have to come up with an idea and then present that to my director and then go out and recruit my clients and then make it work. For instance, I work with cerebral palsy, I have mentally retarded square dancing, mentally retarded pianists, and the like. I came up with these ideas and tried to make them work. Basically what I am here for is to get different ideas that I can take back and give to my director and say, "Hey, let us try this at our center." Then if they work at our center, maybe they will catch on over at other centers.

Boys Clubs: There is a difference then between a building center program and a scouting program. They are totally different. The concept you have been talking about here is of no value to Boys' Clubs and/or Park and Recreation. What we are doing then is that we have clubs throughout the country, particularly in our region, that are operating very good mainstreaming programs and do not even realize it. We have Boys' Clubs that are working with the retarded, we have clubs that are working with special education, we have some clubs that are working with the physically handicapped in isolated programs - not mainstreaming. We have one club down in Bryant, Texas, that has done a fantastic job in the past of working with special education and their programs are from the art to the physical to full-scale education and even, to a minor degree, tutoring these youngsters in their program.

Talking about volunteers, that's part of it because the Scouts are going out to the school. They are securing in-school activities. Boys' Clubs are not doing that. Our volunteers have to be - I hate to use this term - but they have to be under the firm hand and guidance of that professional that you have inside that Boys' Club. The recruiting aspect of this can be done by the pros in the Boys' Club field, but most of this could be done by volunteers or by interested parents of the special education students.

Recruitment is no problem to the Boys' Club. In fact, we don't have to recruit. All we have to do is pick up the telphone and call the school system and the next thing we know they are flooding us with participants in that program. Not mainstream participants, but participants and from this then we have to find and train our staff to work with these youngsters. We use the teachers from the schools to come down and instruct our particular staff person on how to work with that handicapped person, that special ed student.

It is this type of collaboration that you and I have to work with with Boys' Clubs and other building center built programs. You know the Scouting program is good for the Boy Scouts, but that is it. They are certainly not good as far as our type of activity is concerned and I think that is where I am missing the boat on some of these sessions.

Park Program: In my situation, within the city, you have such a thin line of communication that there are things that you can do, can say and things that you can't do, can't say. Whereas the Boys' Club, someone could go out to the homes and ask them for outside help. For instance, I couldn't go to the schools and say, "Could you send someone down to my center and initiate a program?" I could go out and get a friend of mine and do it that way, or get a parent from one of the ARC's or something like that who is involved in my program already to help, but as far as me initiating and going out and doing on my own, I cannot do it.

John Sevier: Would it be fair to say that, in the light of your statements, that in the field of recreation centers such as you are working at, that the program is largely recreational to eat up idle time? No, it is still fundamental.

Recreation: Educational, vocational, therapeutic development of the youngsters.

John Sevier: The same as us in the Y.

Recreation: Our programs are totally different, our implementations of these are similar; but our goals, our objectives of these I imagine would parallel.......

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John Sevier: Developmental?

Recreation: Right.

John Sevier: Good citizenship?

Recreation: As far as recreation, no we are not a recreation center. Off the record, it is a recreational center, but as a guidance oriented organization, that's what we strive for. That is where we are missing the boat as far as the general sessions have been going here. I don't think we know enough about our individual agencies sometimes.

Park Program: With my facility, I can just about get into any type of new program that you want. It can be recreation, academic, any type because I have the facilities there to accommodate many different types.

Participant: Is there anything in your area either in Boys' Clubs or Scouts or Recreation Centers about determining what those who have a handicap like, don't like, want to participate in? What experience have you had in trying to find out what the participants themselves want?

Boys' Clubs: I would have to speak for that from the Boys' Club point of view on an individual club basis and right now I am just familiar with this type of programming in three boys' clubs. There are others doing it, but I am familiar with these three and the one actually involved the special education students into the program planning of this. We also involved fourteen teachers from four different schools that were teaching special education classes. We involved them with our staff, Boys' Club staff and the board volunteers who were on the program committee. We involved the total group in a planning session where they could actually say what they wanted within the realm of what we had to offer and the overall Boys' Club program, which is a diversified program, and they could almost pick their spot.

The other two clubs that I am really familiar with are strictly doing what the educators requested of them. The Panther Boys' Club, for instance, is doing an aquatics program. This is what has been asked of them in years gone by to conduct this type of aquatics program for the handicapped. They have been doing it a long time, but it is not mainstreaming and yet, in a sense, it is.

We have one club in West Texas that is doing a fantastic job with the special education students, again in the area of youth employment and no one knows about it. I didn't know about it until I happened to walk into the club. You know you have self evaluation and the executive started asking, "What are all these young people doing here this time of day?" They were special ed students who get out of school a little bit early and they have jobs that they go out and interview for and the whole bit. It is a tremendous program and no one knew a thing about it.

John Sevier: Otherwise, they have their swimming programs along with what they were doing. They begin with their little "minnow" and as they progress, go from "pollywog" up to a "little fish" and then a "big fish" until they graduate out of the program a fully qualified swimmer. In an aquatic program there is advancement and then some immediate recognition so that the youngster, particularly when you are dealing with the handicapped, is rewarded quickly for accomplishment which helps to build his own self identification and self evaluation and, ultimately at the end, graduate. This is in principal no different than the Boy Scouts advancement program. A person starts off, has the options of picking his own merit badges. It takes 21 to get to be Eagle Scout, but a boy can pick and choose within certain limitations. He can choose which 21 he wants to get among the optional ones so that he can build his own program. I guess this is the same way your girls do.

Girl Scouts: We have extensive program planning. No Girl Scout troop exists without the girls deciding what they want to do. I am sure that you know from your council too, that is the whole crux, that they learn decision making early. If there is a handicapped troop, I know because I was the leader for two years, they do have the girls make their own decisions. They might not get to pick from all 76 badges, they might make a decision between one or two or three that would be appropriate at that time, but they definitely have input as far as their decision about what they want to work on and there is always a progression.

John Sevier: One thing that the Boy Scouts have too that might be relevant to some of your needs is that the boy meets with his scoutmaster to develop a personal development program for himself; mentally, physically and socially. I don't know whether you have that kind of plan that develops between the individual and whoever the volunteer or professional leader is. This is something that really builds upon for the boy and the scoutmaster. I don't know whether you people use anything like this, but maybe this is something that you could use. It becomes extremely important with some of the educable and trainable youngsters who build upon the relationship between themselves and their leader and try to find a way to grow up and become the healthy individuals that we all want them to be. This is something to think about. I don't know, since yours is largely recreational. Is there this thing about being developmental in the Boys' Club and the 4-H? Do you have anything like that in your program?

Dan James: We have an agreement between the volunteer and the youngster, "Here's what I want to learn" and the leader will help him decide. "Here are the activities that you can carry out to learn. What is it that you want?" It is a goal setting process, simple form, simple sheet that is set up at the beginning of the year. "Here is what I want to do" and the leader helps verbalize that and put it down in writing and within a year the leader asks, "Well, did you learn this?" "Yes". "What did you do to learn this?" "I did these things" or, "No, I didn't: and that gives a person basis for the next program he wants to start on.

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John Sevier: What kind of an internal program do you have?

Boys' Club: We revolve more around our group work activities which would be a parallel to what Dan is discussing here. We go into this type of training with our small groups. I am concerned about mainstreaming and the Boys' Club work. I know that we are doing this in individual clubs, that we are separating programs for special education. What frightens me about multiple handicapped people coming into the club is that we may have 150 to 200 boys a day going through the club and then you have to have additional professional people to work with these handicapped people that our staff is not trained to do. We will need to carry volunteers to work with these people and it is rather frightening. I think there are going to be a lot of clubs that will take a hard look at mainstreaming and I think what is going to happen is that more of them are going to start having individual, separated, segregated programs for the handicapped. That is just a general observation from the way I see it today. Hopefully it can work into mainstreaming, but perhaps you can answer this for me. "What do you do when you have, for instance, the multiple handicap?"

Participant: We were talking in one of our groups the first day and Linda Johnston, the cerebral palsy person, said that; realistically, you cannot expect to mainstream every single person. There are going to be, just by the differences in our organizations, times when you are going to have to realistically exclude some people. That is too bad, but there is going to be a place for them in somebody's organization. We just can't realistically expect to absorb everyone.

Participant: I think one of the keys to this whole context is the fact that Linda started it off and we began thinking about this whole idea. It is a fact of life that if a person is blind, he is not going to get a driver's license. There are certain levels that, just like those children that we saw yesterday, they are going to reach. That is it and that is a fact of life. This, I think, is the key to the whole thing we have dealt with here. There are certain things that Boys' Clubs can do that nobody else can do for that small child who lives in that neighborhood right there and this is true of all of the other agencies that are involved. I think this is also the key to what we are doing.

Boys' Club: I see another key to this. I see a key as to 4-H expertise. I see a key as to Scouting expertise. I see a key to the school expertise. I see a key to the Parks and Recreation Club and to the others. I think that what we are trying not to do here is to collaborate with each other. I think that we are so damn individualized that we are all sitting up here tooting our own horn to a different degree and we all refuse to collaborate with each other. The Boys' Club Director and the Park and Recreation Building which is a half mile down the street, we'll say, is offering a physical education program for handicapped and I am involved in an aquatics program. Dan is offering an educational program. Anyway, we are all offering. We can each offer a different type of program and collaborate on these things.

Youth Club Work

Girls' Clubs: I think we are going to have to.

Boys' Clubs: Oh, it's essential.

Girl Scouts: I said that the other day because Girl Scouts are not knowledgeable enough with regard to handicaped or disabled to do this.

Participant: None of us are.

Girl Scouts: So we are going to have to and we don't have the facilities to offer any recreational things except for our camps so we will have to go to other agencies.

Participant: We don't have camps.

Participant: And, again, there is nothing to say that this child can't participate in more than one activity. Take advantage of things.

Participant: The problem is not overlapping. The problem is overgetting.

Participant: Right, and we are all spending money for the same purpose.

Participant: There are plenty of children out there and all of us together are only touching 5% of them. So there is plenty of room for everybody to do whatever they need to do.

Participant: I'd like to comment on something that you have all skirted around and never really jumped into. You commented on selling our programs to the handicapped. If you remember Don Drury's remark, it is one of the first turnoffs, us coming to them and saying, "We want to enlist you, we want to make you a part of it." What about going to the handicapped and asking them what part of our programs help them instead of just sitting here trying to come up with ways we can sell them on being a part of us?

What about going to some special education teachers and educators and saying, "Here are our programs, show us which ones would aid the handicapped." When you talk about the emotionally disturbed, you are talking about people who need a handle on behavioral modification. What do you have in your program that will help that and then you have something that can aid the emotionally disturbed. Talk about the mentally retarded. One of their primary problems is not so much their lack of ability, but their undeveloped ability. What do you have that can help the mentally retarded one small step at a time, trying to succeed when they have been taught failure all of their lives?

When we start looking at our programs in terms of what we have that helps them instead of how we can sell them just on being a part of it, then I think we have one of the keys that we have never really mentioned.

Boys Clubs: I attempted to do that. I said earlier that the three clubs I am familiar with did not recruit. They went to the educators and said, "This is what we have at the club. Can you utilize it in any way during the specific operational hours?"

Participant: That is what I am talking about. If we will begin looking at what the real needs of the handicapped are and then what parts of our program meet those needs, then maybe take it another step as to how we could modify our program a little bit so it then in turn really would meet a need, we may have a program that is fairly good. But maybe with one or two modifications, it would really do something in terms of helping the handicapped.

The second thing is very simple. How many of your agencies spend hours and hours training you in the techniques of fund raising, volunteer management and all these other items? You don't go out and talk to the Baptist Church about scouting or you don't go to a Catholic community and try to start a Boys' Club or go to a rural community and 4-H without understanding the public you are trying to deal with. If you are going to talk to a rural community, you are very well versed in it and its needs and why 4-H is important.

If we really haven't taken time, as everybody is saying, you don't really understand the handicapped. That is one of the things that, as agency professionals, if we don't understand that public, we can't go serve. Until we begin to understand some of the key elements of retardation and the causation and the effects and the specific types of approaches that can help a boy overcome those causes and effects, we are not going to serve the mentally retarded with our programs except simply enlist them and give them a halfway experience. We are not going to serve the emotionally disturbed until we understand the factors that cause it and what a teacher in a school situation tries to do to help that boy. We can then compare, parallel it with our program as to what it has to offer that will do some of the similar type things to help that boy overcome the cause and effect of emotional disturbance. Does that make sense?

Participant: One step further is the fact that I am aware of in working with the handicapped, mentally and physically; is that there are special teachers, cerebral palsy staff, special education staff and agencies and organizations that are set up just to help that particular problem.

Participant: That is true.

Participant: There is also staff seeking out what is available through the agencies that we represent here. There are many ways of cooperation so it is a two-way street.

Participant: That's right.

Participant: It is a communicative effort that really hasn't been adequately met at this point because you have got the community professional people who understand and are working daily with the children we are talking about. You have the agency people here, you have the advocate organizations here, and the advocate organizations and the professional communities have somewhat communicated; but as agencies we haven't really communicated both ways with either of those groups. Its like you said, everybody wants to holler, "I have a good group for the retarded to be a part of if I could just sell it." That is the thing that is going to turn them off. The first thing they are going to say is, "We just don't want to be a number to help you tell the federal government that you serve an X percent of the retarded. That just doesn't interest us."

Participant: And they want to see some action, not fake.

Participant: The second worst thing you can do, as you all pointed out in your school situation where people come in and try something and failed; is unless we match the program to the child, it is going to fail unless we look at the needs of that child. Some programming ideas, some really good ones have been brought up. Arts and crafts are an area that most any child, handicapped or not handicapped, can take part in. Leisure type activities. We did a two-year study in a State School where I worked for the mentally retarded. The major factor in whether or not those retarded individuals could make it in the community on their own when we placed them in the community, was how they handled their leisure time activity. We did not get them back because they could not perform on the job. We did not get them back because their employer was unhappy or that they were dishonest. We got them back because when they punched out at 5:00, they didn't know what to do until 8:00 the next morning. If you have anything in your organization that has to do with showing them how to use their leisure time, that is needed.

You know, organized football isn't going to help the mentally retarded utilize their leisure time. Bowling or tennis or something feasible is what they need. A child that has a handicap can go down to the local bowling alley and say, "I would like to join a league" and someone will probably get them in one so that they will make friends and have contacts. Somebody that likes to play tennis can call one of their friends and go to the tennis court and maybe make some contact. They have really got to look at their activities and how they help their leisure time.

Their vocational training can be of big importance, especially the type of vocational training where you teach them how to handle money and how to find their way down town. You utilize bus routes, what the city government offers in the way of services and that is where you could look again at your city connected facilities. When you first start looking at what the needs of this population are, think of what we offer in our agency, think of some of the ideas that have been thrown out, you will all begin to see that here is a handle that Boys' Clubs, Girl Scouts, 4-H, our City Recreation Center, whoever, can begin to get involved in initially. You may not do it all the first six months, but I think you can remember Allen Sullivan's remark that maybe mainstreaming is the goal and we are talking about just putting the process in motion. I am not saying that in the next six months Boys' Clubs have to mainstream 80% of the boys. We are just talking about starting the process. We are just talking about reaching out to these people.

I can illustrate by a little story about a chicken and a pig walking down the road. They saw a poor family sitting up on the steps and finally the chicken said to the pig, "That's a really poor family and they look underfed. Why don't we give them a nice ham and egg breakfast?" The pig said to the chicken, "That's real easy for you to say, you just make a deposit. For me, I have to make a total commitment."

I think you are going to realize that we are going to have to make a little more total commitment to serve the handicapped in our population than we have for the normal boy who walks in the door on two strong, healthy legs with two healthy arms, a brain that can understand and a voice that can speak very intelligently and say, "Mister, I came to join your basketball program." "Fine son, walk down the hall and turn to your right," and that solves our problem.

The other boy clumps in the door, maybe on two crutches and he has a speech impediment and he says, "What can I do?" He doesn't know what he can do and you know you have eighteen things to do and it is going to take more time to involve that boy. That is where it is going to take commitment, either from our staff or volunteers. Maybe that is something, before we jump into mainstreaming, we ought to go to our Boards of Directors and say, "Here are the great things about it, but here is also your challenge. We can't just do business as usual and serve 30% of the handicapped because we haven't time."

Dan James: I have one more question though. What you mentioned here and what I would like to refer to is network. I still have yet to see anything come about. I do not even know what the population is, the kind of numbers you are talking about, where they are at, what kind of service agencies are going to be involved in doing some networking.

Participant: The school systems have to know how many there are of the population from ages 3 to 21 so you get an initial figure right there. The Board of Education has to know. There are federal laws requiring them to provide an education for anyone with a special need between ages 3 and 21. You can get that at that point.

Nearly all the advocate agencies, Dallas Association for Retarded Citizens, any of those groups will have fairly adequate data on their type of population and its brought on into the adult years. If you want to know how many with cerebral palsy there are in the Dallas area, you can contact United Cerebral Palsy at Dallas or United Cerebral Palsy at Ft. Worth and nearly all of these give you the figures on the adult population. I feel that from the advocate agencies and the school systems you can get a very accurate count.

Youth Club Work

John Sevier: The one difficulty is that you will not know who they are, only how large the numbers are. You will have to attend the open meetings of the agencies themselves to get information. Make your presentation to them and then, as they open up to give you their names and addresses, you can build a file.

Participant: Part of what is so frustrating, especially for people who are trying to zero in on starting something is the vast source of resources that have to be contacted and maybe if people are thinking of trying to serve everybody, trying to be everything to everybody as the common goal of all our agencies; maybe it would eliminate a lot of frustration when you can start to realize that you are not going to be able to reach everybody. If you could zero in, it would be much easier on you and eliminate a lot of frustration. This is true especially state wide. That would be just tremendous because you couldn't even start to gather all of these statistics of all of the different handicaps and all the different places in the state.

Participant: As I see it, awareness is going to be the first step. All I can see there is making our staff aware of the various agencies or the various service groups, or advocacy groups and also the information about the school systems. I think for the most part the parents groups are going to be a good start for most of us to work with as far as having some idea of what the 4-H program, what the scouting program, has to offer and the staff that has to be working with the kids themselves. You know it just has to be in the works. You hear of somebody you might like to contact and interest him in doing something.

CAMPING

by

Marsha Reid
Texas Women's University

Camping and its role in mainstreaming will be discussed at this session. Some experimental ideas that may help you when you are doing training will be included.

We will look at the potential of individuals who have some kind of handicapping condition, some limitation or disability, and what a one-week or two-week experience in a residential camp or even a day camp situation can do. We now have the feeling that we need to work for such individuals and get them involved. What I want to discuss is another concept - *working with people as opposed to working for them*.

My camp, Camp Happy Hollow, which is incorporated in Michigan, has a year-round program. Campers range in age from eight to seventy-nine. We deal with all types of handicapping conditions; autism, mental illness, mental retardation, orthopedic handicaps, blindness, deafness, blind/deaf, blind/deaf cerebral palsied, blind/deaf mentally retarded, and others.

My staff is not unique. However, they are committed to working *with* people to get them into regular agency camps; YMCA, YWCA, Boy Scouts, Girl Scouts, away from our camp. We would like to put ourselves out of business if we can involve people comfortably in other camps. To help my staff, therefore, I hired handicapped individuals including mentally retarded, orthopedically handicapped, cerebral palsied, and also some who were totally deaf.

I had watched one mentally retarded young man, aged 32, who had been institutionalized or living in some kind of protective living environment for over twenty-five years. He had gone through the camping program and had been put into a work program, a maintenance program, so he could feel he was contributing something. He had been in the program for sixteen years. He was too old for the camping program and there were few adult programs in which he could participate.

This young man was taken out of the camping program because it was becoming difficult for the staff to work with him. After so long in the program, he thought he knew more than they did. I decided to put him on staff supervising children. Bill, as I shall call him, was very excited about this opportunity.

I wanted my staff to become involved in the process of looking at new staff. When Bill's name came up, they remembered the difficulties they had had the previous summer. None of the good things came out. There was nothing about how he could follow directions, his dedication, his real concern for and skill in working with people who had problems similar to his. He had had many behavioral conditions throughout his lifetime that made it hard for adults to accept him.

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During this discussion, I found my staff were real bigots. We talked about racism and handicapism being one and the same. I believed we should give some thought to the possibility that the same type of prejudice we have toward races, we have toward the handicapped. This attitude often makes mainstreaming a very difficult process. My staff was composed of beautiful caring and loving people and they were still bewildered and shocked. I still decided to hire Bill.

Bill was expected to go through all the regular staff program. In the competency tests given Bill missed two, three and four questions. Many of my class missed several. A deaf young lady missed seventeen on the first test, the competency test. This was because we didn't interpret for her either by signing or finger spelling. I was fortunate to have one staff member who could sign. When we used sign, we had a great deal of success with this totally deaf person.

Bill had a look that was stereotypic, an interrupted speech pattern, few socialization skills. He hadn't learned to lower his voice in public and talked loud and constantly. He could read and write. His writing was primitive, but his notes were very thorough. Many of the high functioning mentally retarded, whom you see primarily in your programs, have the appearance of a particular syndrome, especially Downs Syndrome children, but they are not necessarily academically retarded. However, they do look retarded and that is where there is a condescending attitude toward them and we are surprised that they can read and write.

Bill's notes were very thorough and he checked them with whoever was the trainer at the end of the sessions. He studied his notes because to him, this was his first job. He had done many menial tasks, but had never been put in a position that required him to exhibit his own personal responsibilities. It was not surprising that he performed in a superior way. I had watched him very carefully the year before and I knew he had many problems. I did not have the time and the sympathy to talk with Bill about men and women relationships, but I got others to help him in this area. In the process of becoming a staff member and working with children, there were no problems. That means that when Bill was up he could help with wheelchairs, campers. He could talk to other staff. He became a model for other staff members. The person with cerebral palsy and all of our handicapped staff were, in fact, models too - young, caring, college-aged individuals. I didn't have anyone on my regular staff younger than 18. Those under 18 were strictly volunteers who were only there for one session at a time.

In the process of modeling we learned that we were more alike than we were different. That was a hard one to learn. We learned people take their time and need time to do different tasks. I don't think this means they are any different than you or me. I think we can be speedy when we want to be speedy and when we want to be lazy we can be very fond of being lazy. That's no different, really, for people who have some handicaps and limitations.

One thing that we need to know is that individuals with orthopedic handicaps that involve some type of paralysis; waist-down, neck-down, mid-chest-down, do take longer to dress. There is a whole routine that each individual has to follow in order to dress himself. Some people who are paralyzed put their pants up over their head and hope then that they are able then to shoot their legs into them. This kind of paralysis could have been caused by a car accident, a camping accident, a motorcycle accident or any other serious accident. An individual who has become paralyzed has to work out a method of dressing and toileting himself.

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If there are individuals with speech problems, people with cerebral palsy, they will also have problems eating. Individuals with cerebral palsy do not have the facial muscle control that normal people have. It is hard for them to close their mouths because there are spasms, almost electrical, that shoot through the muscles, shoot the mouth open. It is very difficult for these people to eat neatly. The food at most camps is also not conducive to helping them with their muscle control problems. Once the staff understands the problem, they will know how to treat people. My staff learned to appreciate the difficulties cerebral palsy individuals have.

Probably 20% of our campers are people you would never see unless you work in an agency such as Goodwill. Many do not have jobs, but want to work - work at something where they can achieve even a small measure of success. This means that 80% of our campers should have been in regular camps. The problem was that they were too old. The campers between ages 8 and 11 we worked with very hard; not only with the camper, but with parents. We found out what was available to them in their own communities because we wanted to get them involved in their own community. The parents were strongly advised not to put them in a totally handicapped group. YMCA's were beginning to have swimming programs including handicapped, and we tried to get the parents to take their children to these so they could learn water safety skills.

We had some conflicts with various agencies, not because they didn't care, but because they didn't understand that handicapped people survive better and acquire better skills when they are not with their own on a total basis. That is a hard philosophy to understand. What that means is there are so many children who are able-bodied, their arms work, their legs work, their heads work, their eyes work, their ears work. There is nothing abnormal about their behavior. Those very, very normal children are often very adept at helping children who are not quite normal, who have an arm missing, a leg missing, a hand missing, part of the brain not functioning.

The orthopedically handicapped folks, those who are handicapped in their bodies, not their minds, are the easiest for us to mainstream because the mind is sharp, the voice is clear, and the words are the same words used by any person. The mentally retarded person is probably the hardest individual to mainstream because of looks as well as the skill development.

In Michigan there were objections by the American Camping Association to allowing people with seizures to come to camps. Nearly 90% of the children in our camp had seizures. They did not have fits - fits are what we have when we are angry. Convulsions occur when the electrical impulses in our brains don't work correctly and force the electricity through the body making us do weird things such as rolling our eyeballs, or staring or withdrawing. Few people swallow their tongues, but an air passage can be blocked by the tongue by trying to vomit and aspirate or breath at the same time. My staff and volunteers have been trained to take care of people with seizures so they can be mainstreamed.

What happened when we mainstreamed? The children came back to our camp for the next year. Why? They were made to feel different in the other camps. They were sorted out. The staff knew who was coming and if they were deaf, blind, retarded. If they were not orthopedically handicapped, most of the children were not accepted at camps. They were housed away from the main camp. This was our battle in Michigan, to ask why this was done? The answer was that it was done for the convenience of the staff. What happens as folks are denied the possibility of learning with a peer who is all there? It doesn't mean that every single person can be absorbed in a group of twelve kids. If you have a cabin that holds twelve and you have one handicapped child, you have eleven AB's (able-bodied or normies - whatever the jargon is that you are familiar with) and one person who has some kind of handicap condition. It doesn't mean that you are going to have success all the time. Many handicapped children have been so protected at home and have not had access to any kind of community involvements so when they go into a camping situation which is a sub-culture, it is a whole new community with whole new expectations. It is a whole new life style that is exciting, that is dynamic, and also frightening. It is no different than someone who is used to a high density urban area and suddenly finds himself in an extremely rural quiet area. That is just as frightening as it is for a handicapped child who has been so protected by mommy and daddy.

There are tremendous things that that child does to get attention. I taught my staff and other staff that I brought in to lavish attention on everyone, not just singling out one person. So we were busy lavishing attention on a number of people and we were able to really disintegrate obnoxious behavior.

One of the problems that we had was the campers would not re-register the next year or would not follow up with the fall program. The expectations in the almost militaristic attitude of the staff in terms of disciplining and controlling groups was so horrifying that it just stripped whatever sense there was of possible achievement away. It gave our campers nothing but failure. Now I know that we lose some children by this over-militaristic structure. We as adults think that that is going to control violence very well, when in fact it can be very, very devastating. The secret there is that when we are mainstreaming and are getting handicapped children into our program, we should really talk with parents. Find out what the parents do at home and if they are militaristic, that is fine. If our staff tends to be very structured, that child is going to fit right in. But if you have a very loose structure, you can do anything you want; cafeteria approach to your programming activities, very little direction. The only time that you really are directing campers is at meal time and at bedtime or at major events like at campfires or cabin challenges or something like that.

That loose structure can destroy a child who needs tight, tight structure. Parents need to know before the child really arrives at camp, what kind of structure and what kind of staff you have. Do you have a predominantly young staff? You will not want to risk destroying some children who need tight structure because a young staff tends to be a little more lazy and tend to be at camp looking more for friends and acquaintances and bedfellows than to work with the campers. If you have a more mature staff, meaning you are bringing in more college age people, then they should at least have some perspective on their own identity and they may be able to handle this whole concept of mainstreaming in a superior way. That doesn't mean there is a great difference between an 18 and 19-year-old or a 16 and 19-year-old. It just means that there might be and that your training and your whole program in your camp is going to make the difference on how that person functions as your staff member.

Camping

Can all handicapped people be mainstreamed? No. Should they be? No. I do not think anyone said that. I never heard that, that is a myth. Can most handicapped people be mainstreamed? Yes. With success? Yes, if we train. There is a hook there and that hook is if. If staff is trained, the success of mainstreaming can almost be guaranteed. It takes time and it takes patience with your staff to listen to myths; "I'm going to catch that if I drink out of the same drinking fountain", "I cannot possibly sit on the same toilet seat", "I cannot possibly swim in the same pool." Now these are 1980 feelings. These are not something from the dark ages. We had a parent who swore up and down that her daughter got pregnant by merely being in a pool with a particular child. All I can say is that mother had thirteen children and she must have done a great deal of swimming.

Myths are very real and they are to be accepted and believed as that person's belief. They are not to be ridiculed or pooh-poohed or told, "Where are you from", because the beliefs are real for that person. Some of you may have been in a situation with a handicapped individual where you now hate all handicaps simply because that one roadhogged, demanded, demanded, demanded, demanded, demanded. This individual may have rolled his wheelchair right in the middle of the road and had an ugly disposition. You should remember that that was only one person. It does take time to work through with your staff the myths and to figure out how to work with people rather than for them. That is the crux, I think. How do we work with people? Where is our own human dignity? What do we want? What do we want to achieve? What is the sense of dignity that all human beings need? What are our needs? What is success? What is achievement? How can we pretty well guarantee them in our programs?

In camping we found that we had to pay attention and train our staff to handle appliances. We didn't know that certain wheelchairs, or some of my staff didn't know that certain wheelchairs, do not go in the water. We could push them in the water. What we did was take an unsalted oil (we used vaseline) and slapped it all over the spokes and slapped it over the hub of the wheelchair to protect it from rusting. Wheelchair tires go flat. That means when you are banging across the ground you may have a flat tire. Wheelchairs are expensive. Those contraptions are very expensive, up to $1,500 for those that you will see in your program. You don't bounce them, they are not toys. They are the owner's legs. They are the legs, the way they can get around the easiest. It hurts to be bounced in a wheelchair. Most children don't complain because they are so excited about being out and off some asphalt trail. Our trails were mostly paved except for our high risk challenge program. We had people that we would get up on a 30' wire and come crashing down with a navy hold wire. I am sure there are many people who will say, "That can't be done. You don't put someone who is paralyzed up on one of those because when they hit the ground they are going to ruin their legs." Or, there is the other side which is, "Go ahead and get someone who is paralyzed with their legs up on one of those things and when they hit the ground, they won't feel it."

We had so many challenges. I am a Girl Scout. I went through the Brownie and the Girl Scout program at a time in the state of Oregon when survival camping was very real. We put packs on our backs and we took off. We had tremendously risky activities. We learned to rappel, we learned to climb. We learned to hike and handle ourselves in white water. We learned many things.

Camping

Campers at my camp learn the same things and can do them exceptionally well. We have white water canoers. We have kayakers. We have campers who can put a carbide lantern on their head and go spelunking, go down in caves. We have folks who can stalk the wild asparagus with the best of us, who can identify very quickly and readily what is edible and what is not. We have those who can give all sorts of hints on how to cook, who know fork cookery and stick cookery. There are those who can use reflectors, who can make a reflector. There are women who can handle their own personal hygiene needs with various reeds and know which reeds to use, and know how to discard properly and know how to take care of the environment.

We have campers who know Roger Tory Peterson's Field Guide Manual. These campers are called retarded, deaf, many names; but they are people who can do things. In planning these activities, I felt that my staff could protect the health and safety of these campers. Our sessions were structured to allow time for those who might need a little longer time. We had hour and a half sessions for boating and waterfront activities. We had creative dramatics. The campers made their own films and costumes. If I saw a camp member doing something for someone, I discussed the matter with him. If he did this again, he was fired.

We did not do the projects for our campers. We planned how long it would take to do the project and did it with them. We sent nothing home from camp that a staff member had done; nothing. There were no staff member's initials on the back of the ceramics that the campers did. They dug their own clay, found out what clay looked like, how to go dig it, how to clean it, how to strain it, what consistency it needed to be in before they made their projects on the wheel or by hand, how to use the kiln, how long things had to stay in the kiln. The things that did go home were camper produced. We did not do popsicle sticks. We did not work with leather mainly because we were operating on a shoestring and secondly, because we had all the natural environment to pull from. We were able to get a tremendous amount of donations, some as much as $100,000 in one lump sum.

Our campers were able to develop their own skills so when they went over to the other camps they tended to be a bit bored because they had been challenged. At the normal camp (a camp that they really wanted to go to because they finally got into the Y where they had been going in the fall and they had been going in the winter for swimming and basketball) they were not challenged. They had been looking forward to camp with their friends with whom they had been in school. They were going to camp together and then they were separated in camp. We should try not to separate them from those friends. They were bored because they were thought of as not being able to produce.

Our campers were bored and they wound up coming back to Happy Hollow and we, of course went through the whole process of working with the community again trying to find out what happened. Each time we found out that our campers had been segregated, they weren't being mainstreamed. They were at camp with normal children, but they were sitting on the peripheral almost always. Instead of going out in the canoe, having passed their swimming test and being able to canoe, they always had to go out with a staff member.

Camping

I guess what I am trying to help you understand is that if you have behavior problems, it does not make any difference if it is a handicapped child or not. We would handle behavior problems the same. We would be consistent. When we want children to have a good time, then handle that the same way too. We don't have to have a different way to have a good time. If there is a camper who is severely misshapen, but who really likes to canoe and who has proven that he can pass the swim test and would be safe if the boat or canoe capsized, one of the easiest things to do with a canoe paddle is to use rubber bands. Take two large rubber bands and knot them together so that you have two loops. Put one around the wrist of the individual and the other around the paddle because the natural spasm will feather and one of the better featherers is someone who is severely involved with cerebral palsy. The rubber bands will allow that canoe paddle to still be in the hand if there is the contraction and the flexing motion within the hand. It just saves someone from scooting over and picking up the canoe paddle and then pretty soon saying, "That's a drag."

We learn things very, very practically. We also learned that handicapped individuals can be turned over and capsized. This is a regular situation even though I have some staff members saying, "Marsha, we shouldn't do that" and wringing their hands and going through all the "Are you mean to handicapped people" routine. What we are going through is the normal routine of making people safe in the water because we have many water activities. We had no hydraulic lifts. Our docks cost right around $38,000. We have nothing special really to accomodate handicapped. We made our ramps by filing down logs. We didn't want to pay for wood to build ramps and we are in a particular part of the country where, with the cold and the warmth, we couldn't really use concrete. It cracked and it was no good as the fishermen put salt down so they could get their cars out and salt would destroy the concrete. We simply hauled in logs and shaved them down with a plane to make things a little easier for the wheelchairs.

We also did a great deal of crawling on the ground. Brightly colored, heavy rug yarn was tied to wheel chairs so campers could find their own wheelchairs and then pull the chairs along behind them as they crawled along the ground. Some campers preferred to do this, others preferred to be "baby." Campers were taught to be self-reliant. If they wanted help, it was there.

We fought with the American Camping Association and other agencies who were afraid to let people with seizures into their camps. They were really afraid because they did not think it was safe. I have seen seizures and I have had terrific seizures, but no one kept me from climbing a tree, or out of a swimming pool or skiing or anything else. I didn't know I was different until I was labeled. When I was labeled, not only was I different, but I had some real concerns about where I could swim. I had to lie to get a driver's license. I had to lie to get a job and I lied to keep my job. Labels are no fun and they stop many of us from being able to realize our full potential as human beings. They would have stopped me from being able to grow up with you. I would not have wanted to be in a special school because I would have grown up with people who are forced by their staff to be dependent. No matter what you think of institutions, they are not the best places to be.

Camping

As we move to accept mainstreaming; we each, individually, have to look inside our own minds to figure out the risks that we have. What do we think that certain handicapped people can't do? Write these down to remind yourself and check them out. It is true it does take longer to do some things, but there is hardly anything that you can not do. You just have to do it a little differently with the element of humor and fun. You can pretty well create a camping environment of a mainstream nature with total success. Granted, you will always have that individual who is going to have a rotten time at camp. That person probably didn't want to come to camp anyway. It was not that camp turned them off. They typically did not want to come to camp anyway and they are angry for whatever reason. Maybe there was a divorce going on in their family and they don't want to be away. They may be afraid. Some of our campers have never been with people who are normal and all of a sudden they are plunked down into your program. It is just as unfair for them to be plunked as it is for you having to plunk that plunker. It is not easy.

I hope that you're not getting from me the feeling that it is easy to mainstream and that any and all of us can, in fact, work with mainstreaming. While I agree that we can work mainstreaming, I don't agree that all of us can do it. It goes right back to training. It means that you have to have the commitment to understand disabilities and there is a great deal to know. In every urban area there is at least an association or a chapter or a council dealing with each one of these handicapping situations. I tell my parents to talk to at least two different people, not one. Do not buy one person's story. If it is positive, that's a little safer, but if you get a "no", call again. If it is necessary to talk to three or four people in that agency, then do that. Parents really have to fight. Often there are many difficulties in keeping their family together as a complete family packet so the children we work with have a harder time having both a mother and a father than other children. The financial burden on a family that has a handicapped child is enormous. The hours and hours of guilt and bewilderment and wondering why and what they are doing wrong, "why me", take a horrible toll so parents may be very hurt. They may snap at you. They may be very untrusting. They may just dump their kid and drive off. They take many different attitudes, but unless you have had a handicapped child, do not make the judgements that make parents seem to be really poor persons. They coped as long as they could, as hard as they could, and some of their coping is not good and they have lost their mechanisms. When we get these children at camp who have been so protected and haven't been able to be mainstreamed because mothers are afraid (because you and I have really done some cruel things in the past. Because no one told that mother to try two people in the agency. They tried once and they became turned off), that child does need a little more sensitivity, but that doesn't mean special attention. It does mean awareness, but it doesn't mean necessarily that it has to be one on one. If you are going to have a one-on-one situation, I would suggest that you bring in volunteers so your one-on-one is not core staff.

In terms of looking at using any program effectively with any handicapped child, you are just going to have to accept on my blind faith here. You are going to have to trust that I do know what I am talking about and there is not one activity that your people cannot do in a mainstream situation because you have able-bodied people right next door. If you are segregating, you are in trouble and you are going to remain in a difficult situation. Your staff is going to get burned out and they are not going to like you very much. They may not return the next year. So watch out, watch for the grouping.

Camping

Question: You were talking mostly in terms of children. Is that because there is a lack of community resources for mainstreaming age 21 and over?

Marsha: Yes, there aren't very many adult camps - most of them are generally family camps and are not for singles or else the cost is very high. Our program costs $60 a day and these were not rich children and they stayed with us two full weeks. We have all sorts of ways to get scholarships, but it is terribly expensive.

Question: I think it is hard to motivate the community too to donate in terms of adult disabled. Children disabled are cute.

Marsha: Yes, but they grow up and then they are not so cute.

Question: Are we destined to keep them inside?

Marsha: I hope not. I hope that we can open up our community based programs which work very nicely according to Linda Barnes who will make a presentation in the next hour. But the idea here is to be able to develop community programs, not splashy summer programs or anything else, but community programs where people can come down and they are not going to catch anything. You are not going to be ripped off because someone has a behavior disorder. You are not going to be socked in the nose because someone is deaf. You are not going to be drooled on because someone is retarded. Any of these things may happen, but they happen to all the populations here.

Our adults were born a little too early, but we are getting there. Mainstreaming is hard, it has been fought, it is misunderstood, it is scary and all these other things, but we are getting there and I don't want my camp to continue.

Question: Can you take another approach to your camp instead of closing it? Can you open it up to the normies?

Marsha: We bring the normies in and we do run a year-around program now, but in our summer camp program we do not have very many parents who want to send their child to a camp that has a history, since 1957, of being for the handicapped.

Question: The problem that the handicapped have is bounding off of this unreceptive atmosphere when they are segregated. It would seem to me that our approach might be to teach the normies how to handle it.

Marsha: We are working on this a great deal, but it is rather spotty. We are having these same problems coming up in kindergarten and preschool and we do have some of those programs depending on where you are and what part of the country. It really does. It is geographical, state-wide. It is attitude-wide in State Departments of Education. Many times we look at our news carrying agencies. Project MAY is the beginning. It is really beginning to blossom. Whether it blossoms as a flower or a weed is up to us. There are some gorgeous weeds around and some really beautiful flowers and we have our choice. That is our challenge - to go back and spin off program ideas, talk with our staff. If we have more awareness now, it is mainstreaming and that is what it is all about.

Camping

Question: Could you compare the mainstreaming process to the integration process?

Marsha: Yes. That is why I approach handicapism and racism as one and the same. The words are different, people behave a little differently, but they have the same exact problems which are just as idiotic and ill-founded and ridiculous.

Question: One thing I was looking at. If you bring in all handicapped workers who are staff members and you.......

Marsha: No, I only had four out of a staff of sixty-four.

Participant: Oh, I thought they were all somewhat handicapped.

Marsha: I worked with 50% staff handicapped in Indiana and that was incredible.

Question: I was wondering how you could mainstream that program.....

Marsha: I think four out of sixty-four was a good number for my staff to absorb because I had four very different kinds of handicapping situations. It was exceptionally difficult to accept someone you saw as mentally retarded. It was difficult to accept someone you saw as deaf and that posed a, "What do I do now?" It was very difficult bringing someone in who was severely involved with cerebral palsy and someone who was mildly involved with cerebral palsy.

Question: Again, don't you feel that it is somewhat more handicapping for a child to come to your camp and learn all these things when in an ideal role, in the real world, they are not going to learn all these things at another camp? It seems to me they have had the best that they can have and they are back and maybe you have handicapped them more.

Marsha: We have wrestled that one, but we are still committed to teaching as many good leisure skills that a person can do on his own, with friends, and not have to go to your camp and my camp. I am talking about things that need to be done with another person. That is a start towards getting handicapped people out in their own community.

COMMUNITY PROGRAMS

by

Linda Barnes
Texas Women's University

Community programs for the handicapped abound in some communities and are few or non-existent in others. I would like to share some ideas with you which may help you in organizing activities for the handicapped in your community.

I am a graduate assistant in adapted physical education at Texas Woman's University in Denton, Texas. One of my related jobs is to direct the Sunday Afternoon Recreation Program for the adult mentally retarded persons who live with their parents in the community. The purpose of the program is to provide recreational activities while giving the participants a chance to interact with peers, to learn and to use social skills, and to attend community activities such as plays and musicals. The Sunday program is the only program for the retarded in Denton except for the Activity Center which is provided by the Association for Retarded Citizens. The Activity Center meets during the week and the ARC Director had to look into several places to meet as one was not readily available.

Last fall a new director for the Parks and Recreation of Denton was hired. The Executive Director for the ARC and I went to visit him to find out if any programs were being planned for the handicapped. We explained that I directed the Sunday Program and used the recreation building, but when other groups were scheduled, we had to go on a field trip or not meet. We also stated that our interest group could not readily join in activities without prior experience in the activity, and therefore could not blend in well with the schedule of regularly planned programs. The director thanked us and said he would talk with his staff and would be in touch with us.

I returned the next day to schedule my Sunday group for the semester and I also offered my help in planning any programs for the handicapped. I explained that I had worked at a day camp for the physically handicapped in Illinois. I told about the Western DuPage Recreation Association for Special Populations which sponsored the camp and also other camps for the various disabilities. This association also sponsored family nights out, trips to the ball park, and other activities on a year-round basis. The program director thanked me and said she would contact me in a few days.

In a few weeks, the Executive Director for the ARC and I received an invitation to sit on a steering committee to develop programs for the handicapped in Denton. Many other interested people from the community were also asked to be on the steering committee. The task force decided that it would be best to begin with a few programs and then build from those. It was decided to offer a family night out for the parents to go shopping while their children were entertained with movies, games, and snacks. This program worked well and the recreation staff were pleased with the turnout. The other program was for the adults who were attending the Activity Center. The recreation staff would teach games and cooking skills to the adults at the new recreation facility. This program was also a success and is still continuing with other activities being added.

The biggest problem with starting new programs is how to find the people who would want to participate in the activities. The task force suggested advertising in the newspapers and on the radio and television. The ads asked people to suggest names of handicapped people who may be interested in the programs and to contact the Parks and Recreation Department. There were three responses to the ads. We know there are people in the communities, but how do you get them to get involved in the offered programs? Perhaps some of the people do not consider themselves to be handicapped - disabled, yes, but not handicapped. Society must learn to change their terminology. It is the able bodied person who imposes labels on others without learning about the person as a person. They see a disabled person and immediately judge the person to be handicapped because the person is in a wheelchair, using a cane, or talks or walks funny. That is not what we should be saying. We should allow the disabled person to exercise his/her capabilities to the fullest extent possible and make every effort to help him/her do so. It is the "normal" people that impose barriers and roadblocks to the handicapped, rather than realizing that the individual does have thoughts and feelings, and capabilities. The handicapped persons need a chance to realize their potential and should be encouraged to do so in every way possible.

Linda Johnstone is also on our staff at Texas Woman's University. Linda is a victim of cerebral palsy and uses an electric wheelchair to get around the campus. I met her the first day she arrived on campus and introduced her to a young man who was also a graduate student at TWU. He too has cerebral palsy in addition to being visually impaired and deaf. He also has an electric wheelchair. The young man led the way as he took Linda, his father, and me on an accessible route around the campus. It was interesting being with those two individuals because people would address questions or comments to the father and myself rather than the two individuals in the wheelchairs. Linda finally looked right at one person and said, "I can talk." This is the way we treat handicapped persons. We see their disability, label them as not being capable of whatever, and that is where they stay. We really need to educate others to the fact that the handicapped are capable of many things if only they are given the chance to show what they can do.

One of the things that I hope you people will go back with from this conference is knowing that people with handicaps are people. Maybe they can't walk and maybe they can't talk. Maybe they can't hear, but believe me, they have thoughts and feelings just as you and I do. Think how hard it would be if you had something happen to you right now and you couldn't talk and express yourself, and you had something you really wanted to say. You really had to get it out and you couldn't do it and you couldn't move your arms either. How frustrated would you be, with people looking at you. Or they might just go on by you and not ask you a question at all when you really had some information you needed to get out. How would you feel? You might have all the knowledge in the world locked up because you are a good reader, and intellectually you are pretty high on the scale. You have it, you just can't express it like everybody else. How frustrating would that be?

I thought of that when I went to Camp Soroptomist the first weekend that they had their weekend camping. I had a young cerebral palsy girl who couldn't talk except just a couple words. She could say, "Mom at home", and that was where she wanted to be, "Mom at home." She had a little pointer she wore on her head. It had a velcro band that went around her head and a little pointer made of steel that comes down with a little eraser on the end. She had a board on her wheelchair and had little symbols on it. It said, "I want", "to", "have" and then "home" or "food" or things like that. When she wanted the pointer, she'd blink her eyes. She had beautiful long lashes and the pointer was in her backpack. So I said, "Do you want your pointer?" I got it and put it on her. Then it was, "I want to go home." She had been there an hour and a half and was crying the whole time. I'll tell you that spending a weekend with that young lady really awakened me to frustration and needs and feelings of disabled persons. She had to depend on me for everything; to get where she wanted to go, everything she wanted, to eat, to be put in bed. All the things a person needs during the day, I was the one to do it. No wonder she cried the first hour and a half. She didn't know me, I didn't know her. She had been to Camp Soroptomist before, but she didn't know me. Think how frightening that would be for you to be put in a place where you didn't know somebody else's language or what they did and are dependent on somebody to get you everything. It is pretty scary.

As agencies in the community, how do you get started? Where do you go? What do you do? What services do you have that you can offer people who really need them? You have sat through all these sessions and heard all these wonderful people give their ideas and personal experiences and things like, "Hey, you can get out there and do these things with people."

You must have thousands of questions and we haven't had much time to respond to them. We have been responding to books. We have been responding to interactions with people on a one to one basis, but I know some of you must be totally frustrated because you came here to get that one magic answer and so far you haven't heard it. You are feeling a little bit deflated like, "I spent all this money and I still don't know what I am going to do or where I'm going to go or how I can make contacts." I'd like you to think for just a second what questions you may have so that we can try to answer for you. Since 1981 is the International Year for Disabled Persons, a list has been compiled here about different directors and the Athletic Associations for Physically Impaired, Parks and Recreation Departments. It is from the Texas Planning Council for Developmental Disabilities. By the way, TWU is hosting a basketball wheelchair tournament the 13th and 14th of February so that information is out on the tables. There is also information about bowling and Special Olympics. Special Olympics, by the way, is specifically for the retarded. There is information about football, gymnastics, soccer and many other things. If you would be interested in getting one of these when it comes out in print, we will have a paper for you to sign your name and address where you might be able to secure this. It would be very valuable for those of you who are trying, maybe in Scouting or whatever, to get some things going. You might find some athletes to call who would give a plug to your program.

Question: Would you elaborate for me again, is it IED?

Linda: IEP is an Individualized Education Plan, or in some schools, Individualized Education Program. When 94-142 Public Law came out, it stated that each child who has a handicapping condition and is placed in a special education school or other type of special education must have an individualized education plan which means that teachers and the parents and perhaps doctors or school nurse, anyone that is concerned with that child in the school setting, must get together and look at the child's abilities as well as the difficulties and find out what that child needs to work on to make them educationally available in that school so the child will get the best education possible. The adapted physical education person, if there is one, is required by law to sit in on that, or a regular physical education person if they don't have an adapted PE person. They write up this child's needs. Maybe he needs first grade reading. If he is in third grade and needs a first grade reading book, he needs to work on that. He needs to have daily physical education. That is required by law. He needs to have second grade math. He needs to have extra help with social studies. This kind of information has to be written out, signed by the teacher, signed by the parents. The children must have an IEP if they are in school.

Question: What are the benefits?

Linda: It helps the agencies who might be able to offer services. An agency might have an adaptive swim program for the handicapped which the school does not offer. Swimming may have been prescribed as a good program for a child because it relaxes him, strengthens his muscles. Also, it is possible for him to do things in the water he cannot do anyplace else. If you are a parent, you may know the Y has such a program, but it is only offered at 10:00 a.m. If the school has no program, the parent could request it be written on the child's program that he could leave school at 10:00 a.m. on the day or days adaptive swimming is offered. Parents are responsible for transportation. The law also states that anyone who is handicapped must have an IEP if they are in Special Education.

I have a film I'd like to show you, a film from the Dance for the Handicapped. It is called, "A Very Special Dance." You can get it from the National Dance Association, but I think it points up some things about people and what their capabilities are. It is by Ann Riordan who is from Utah. She will be down at TWU this summer and for two weeks will give a workshop on dance for the handicapped. TWU is also having Arts for the Handicapped April 3rd and 4th and that will be integration of art, music, dance, and physical education showing kinds of things that people who are handicapped can do. The information is available from TWU, Dr. Claudine Sherrill. Housing arrangements are available which I believe cost $9.00 per night. If you are interested, it must might supplement whatever programs you are trying to do.

FILM SOUNDTRACK

I started working with Dance for the Handicapped ten years ago. I danced for years myself. I loved dance. It meant everything to me and then when I was about 24, I became physically handicapped and could no longer perform. I had rheumatoid arthritis and I started to go into special education and become a classroom teacher. What happened was discovering that I loved working with the handicapped students. Why couldn't they enjoy the joy of moving and dance even though maybe they had some mental or physical difficulties.

I start with a verbal command and if I'm not getting any response, I try to make eye contact first. If I don't get that, I go to where their eyes are. If they don't take the verbal command or the verbal cue, then I will touch. If it is the arm I want to lift, I will touch the arm so they are getting a kinesthetic feeling of my hand on theirs. If that fails, then I will manipulate and leave it and try to get it as high as they can reach it. There are both right and wrong ways to move your arm. There are many ways to move your arm and if you are handicapped and can't quite move it up as high as you would like, that's still right. I am tickled when they give me their best shot as often as they can. I am amazed and I do push them. I am very strong.

People in a wheelchair, their wheels are a part of their mobility. You don't want people to just see the wheelchair, you want them to see the person in the wheelchair. I found from students they are excited about being able to do something different in that wheelchair besides having someone push them. For every move that we do in a wheelchair, I have to take into consideration the weight of the person in the chair, how heavy or wide their wheelchair is, and the physics involved in putting another person on the wheelchair. We are risking a great deal and every time I work with a wheelchair person I have to weigh all the problems that could happen. I am trying to help them extend themselves beyond the wheelchair.

The past year I was invited to a conference in San Francisco and they wanted to know if I could bring my performing group. It was far beyond my wildest dreams that we would ever go to San Francisco, but the trip down was lovely. The experience in San Francisco was fantastic, something that many of us had never, never had a chance to do, and it was just glorious. The audience loved us, the group loved San Francisco, and I loved being in San Francisco.

The handicapped are so visible and so obvious that the first things you see when you see one of my students are their handicaps. It is normal and natural that you may be startled when you first come in contact with them and as they begin to move and present themselves through their dances. As the students start to move,there is almost a joyous response to see how much love they are presenting through their dances, how they are totally involved in what they are doing, how they really do feel about what they are doing. It is so noticeable. You really do see it happen right before your eyes. I have had so many people say that to me. They have seen my group from the beginning and watched them grow all these years and have watched them continue to grow. We don't seem to reach that plateau where there is no more improving. Their sensitivity is getting greater and they are relating and being sensitive to each other. They are not just totally concerned with how they are moving and how their body moves, but how their body moves in relation to another person.

This girl really responded well right from the beginning. The first two did their own choreography. I asked her to work with that scarf so that she was manipulating something other than the space. I have, for instance, had Duke with me the whole six years that I have been at the work activity denter. His concept of movement was always very sharp, vigorous, strong and also his concept of who he was; very masculine, macho, vigorous. I have been working for a long time to introduce the idea of slow and tender and gentle. It is called, "A Song for Duke", and it is his first approach or the first time that he's actually made a choice of moving slowly. You get glimpses of tenderness with him.

I think today we talk about the beauty of staying young and being active and being healthy so we block out someone that has a crippled hand or someone that can't see or someone who has to be in a wheelchair all of his life. At the end of the concert I usually like to end where I have five people from the audience, who want to, who feel good about coming out onto the stage area, to dance with them. It is very important that you get close to one of my students. By the end of this finale dance that the audience and the students do together, there is an exhilarating applause and screaming and hugging of each other. It is very thrilling because I think you need to have that kind of contact actually with anybody, but especially with someone who might be handicapped. Your first impression would be to be put off.

Linda: Comments about the film: It adds to whatever we have been trying to say. The handicapped are people. They are capable and they are out in our communities and sometimes it is going to be a matter, I think, of agencies and people who are concerned with such people to walk outside the doors and say, "We have a service and we need you and this is what we would like to find out. What can we do to make you be the person that you want to be?" You keep that in mind and I think everybody will have success stories.

QUO VADIS

by

John C. Sevier
Boy Scouts of America

It is quite a trick to be asked to try to synthesize what has happened here and hopefully bring you along the road that I see. *Quo vadis?* What does it mean? It's from the Latin and means "Where are you going?" More often than not it was said, *"Quo vadis amieus?"*, which means "Where are you going, friends?" After a while it became almost a password/challenge situation among the Christians when they were being harassed. The question was asked *"Quo vadis amieus;* where are you going, friend?" The answer would be, "I seek He who is called the fisher of men" or "I seek the rock upon which His church is to be built." It's the kind of thing that I think we ought to think about a little bit here. I will try to guide you through what I see, or what I have seen.

We have all been through a very valuable learning experience; learning more or learning less; learning some hard facts; learning some relationships and ideas, and probably have received quite a bit of help that was stretched over two days, in three calendar days from noon to noon. This learning has taken place in at least two domains as the educator would call it; in both the cognitive domain where we can learn to know things, learn to know ideas, where we learn a known fact; and we have also learned in terms of the effective domain where we learn relationships through practice or activity.

That learning experience consisted of a review of our *value systems;* a review of our present knowledge in respect to the handicapped. It has been impressed upon us all, that as much as we may know, we have to learn more. We were confronted with new ideas, new values, new knowledge that others had that we did not have.

A learning experience also includes, as you stand back after comparing what you know with what you have just learned, evaluation. You have evaluated or should have evaluated the impact of those new ideas on your system of values, on your prior knowledge. If the learning is complete, there is always an appropriate change as you integrate into your thinking this new knowledge where it is appropriate, and reject the knowledge and values when it is appropriate. Thus, you change your former *status quo* to a new *status quo.*

How did we bring this all about. There was an interchange of ideas and experiences and values from among other things, 48 conferees. We also learned something else. Not all of the conferees had visible handicaps, although probably every one of us in the room has handicaps. Some of the handicaps are quite obvious, but most of the conferees had no visible signs of any handicap. These people came from eleven national youth agencies, and many resource groups, from both the educational and community sectors. Most of the people here were professionals. A few were students who may some day become professionals. Only one or two volunteers were present. The agencies represented were the Boy Scouts of America, The Girl Scouts, Goodwill Boys' Clubs of America, 4-H, The Jewish Community Center, YMCA. There are others who are not included in the original support list, but because of their interest and concern with the least of our brethren, they were present to learn more.

What transpired to bring this learning experience about? First of all we heard from Dr. Allen Sullivan who was provocative, ebullient, vibrant, and in fact became very controversial. I wonder how many of us will still look at Grimm's Fairy Tales and say that they are *not grim*. I wonder if any of us, from now on, will ever look at and try to teach our grandchildren any of Mother Goose's rhymes. There have been second thoughts as to how we are going to imprint them from that point onward about their attitudes toward others less fortunate than ourselves. No way, I had never thought about it and I was shaken up by the idea. It was beautiful.

We also heard from a consumers' panel. It is not often that we, who try to do work for others, get a chance to stand back and listen to what *they* think *they* want *us* to do. And, of course, I don't think anybody could have listened to Miss Johnston without being thrilled. There was a clear, lucid, vibrant mind and personality within, unfortunately, a body of a person who wonders how fast and how far she can go. I didn't say that she wouldn't go, it will just take a little longer, a little slower to get there. I was tremendously impressed. She was lively, provocative, incisive.

The panel was a good stage-setting for our taking a look at Manual I, Mainstreaming Personal Values, where we were asked to take a look at our personal values; to consider our grasp of the terms that deal with handicapped individuals; and then have them compared to some objective statement in contrast to our subjective opinion at the time. We had a chance to go through and exercise some story telling, to try to understand where our fears come from. In one part of Manual I we were asked to consider, if we were to be in an automobile accident and traumatized, what handicap would you fear most? I think all of us can understand what I would have said the first time I went through that manual a year and a half ago. I'm speaking - the fear that I have is the loss of all oral communication. I would have been wiped out as a *teacher*, not as a mind capable of transmitting ideas, but as a lecturer, as a teacher.

We had a stage-setting also for Manual II, A Guide to Development of a Program. The stage setting was set for us by Project MAY and what is being done; by Project Arts, where they are successful; and by the Boy Scouts of America with their special program that they have at Houston, Texas. What did we try to develop for ourselves in Manual II? We tried to understand the governing elements between goals and objectives; something that we can approach, but probably never fully embrace (goal) - the mainstreaming of all of the handicapped. There are some objectives that we will have to attain in order to make that goal successfully. It involves proper planning both in the short term and the long term for personnel, for plant and equipment, and above all else, money. We had a very vivacious luncheon speaker and she tried to tell us how to make our resources work toward the end that we had sought in mainstreaming special people.

We then went on to Manual III - Your Personal Guide. We were asked to do a little self evaluation. We were given some exercises that, with time, would give us a means of gaining confidence to step out and say, "I will do this for others, I will help others in this way." Perhaps one of the biggest difficulties we have is bridging the gap from mind to mind; the communication gap was another exercise. We seldom, if ever, all use the same meaning for the same word. As a result, an idea in one person's mind, conveyed to another through the word, may be significantly different!" The function of management is to maintain the *integrity* of the assets." I wonder how many people know the context in which that word "*integrity*" is being used. Does it mean honesty, which is about the fifth or sixth meaning in the dictionary? The first definition says "unity of purpose, unity of orientation, unity of use" so that we now translate the statement as "the function of management to keep the assets together to earn a buck." When we do this we are communicating outside the academic world. We have to get to that level. But remember this: when we try to communicate with each other, we must struggle to determine what the other individual meant.

We were also approached with the learning law "Tell me and I may forget, show me and I may remember, let me take part and I will understand." I urge that we go back and think this thing through. For eight weeks, work at trying to put your plan and program into existence. At the end of each week stand back and look at yourself, and assess what it is that you have learned. There is no learning that has any value unless it is put to use, and then evaluated.

After going through the eight week exercise, it is time to look again at your diaries. These were put together to help you see what you had done in the past and whether what you had done was right or wrong. Each of you should review your diary and see where success was achieved and where it was not. Anyone who wants me to look at his diary should xerox a copy and mail it to me. I will evaluate it and send the report back with any suggestions I might have to offer.

We went through several new learning techniques. It has been said by one education philosopher that "If you tell me, I may forget; if you show me, I may remember; but if I take part in it, I will learn." We have done everything that we could to bring the learning techniques together. We haven't always succeeded; perhaps, moving out on your own, you will fill in your own gaps. We saw some demonstrations, activities for the developmentally disabled; three charming little children; we saw the blind strike a ball with a beeper inside of it. I wonder how many of us would have believed that that could ever have happened until we saw it.

Then we had a chance to see some displays and some further demonstrations. We saw a splash and a common little round table on youth programs. We saw and heard something that was elusive, candid, provocative in a presentation about camping for the handicapped. We even heard words that we ordinarily would not have expected to hear, but they were succinct and to the point, about dealing with individuals with disabilities when they are taken out in the woods to camp. It was probably one of the most forthright, honest presentations that any of us had a chance to see.

Quo Vadis

Our eyes were further opened when we saw some filmed ballet exercises by the profoundly retarded. I don't know about the group, but I love ballet. I was moved by what I saw, I had never seen such a demonstration and I would like to show that film to many people I know. I think it would be as eye opening to them as it was to me.

That is where we have been. We are going to leave this room in a few minutes. I am going to throw out to everyone, once again that question; "*Quo vadis*, where are you going?" Is the answer going to be, "We are going to mainstream all our members/youth with special needs" or is it going to be "To *FIND* the mainstream for all my individuals with special needs through my agency." If it is the latter, then our job has been accomplished. Thank you.

PROJECT MAY PLANNING COMMITTEE

Dallas/Fort Worth, Texas
February 1-3, 1981

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Page Two

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(Additional information not available at time of printing)

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DALLAS/FORT WORTH
February 1-3, 1981

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The Inclusive Mainstream

Ramada The O'Hare Inn

Des Plaines, Illinois

February 9-11, 1982

Mainstreaming Activities For Youth
(Project MAY)

A Project to assist youth serving agencies in planning, developing, implementing, promoting and evaluating a collaborative program to mainstream handicapped youth in regular programs.

P.O. Box 1781, Longview, Washington 98632
Phone: (206) 577-0243

PROJECT DIRECTOR: GRACE D. REYNOLDS
PROJECT OFFICER: WILLIAM A. HILLMAN, JR.

AGENDA

THE INCLUSIVE MAINSTREAM
Ramada The O'Hare Inn
Mannheim and Higgins Roads
Des Plaines, Illinois 60018
(312) 827-5131

February 9, 1981 - Monday	ROOM	SESSION
9:00 a.m. - 12 Noon	Outside of Tower Salons C & D	Registration
	Tower Suite	Staff Briefings
		SESSION I
12:00 Noon - 2:00 p.m.	Penthouse	Luncheon
	Ballroom	Keynote Address The Inclusive Mainstream Julian U. Stein, American Alliance for Health, Physical Education, Recreation and Dance (AAHPERD)
2:15 p.m. - 2:45 p.m.	Tower Salons C & D B-1, B-2, G-2	Small group discussion in response to the keynote address

Facilitators	Resource
Daryl D. Jenkins, Project MAY	Eleanor Cameron, Bernard Horwich Jewish Community Center
William P. McCahill, Boy Scouts of America	Wendy Fegenhols, Schwab Rehabilitation Hospital
John Sevier, Boy Scouts of America	Beverly Hutchinson, Girl Scouts of the U.S.A.
John Sullivan, Friendship Facilities	

2:45 p.m. - 3:00 p.m.		Break

A project of the National Council of the Young Men's Christian Associations of the United States of America. Corporate Body: National Board of Young Men's Christian Associations. A special project of the United States Department of Education, Office of Special Education and Rehabilitative Services, Office of Special Education.

February 9, 1981 - Monday	ROOM	SESSION
3:00 p.m. - 4:15 p.m.	Tower Salons C & D B-1, B-2, G-2	Mainstreaming: Personal Values (Manual I) Small group discussion Facilitators: Daryl D. Jenkins, Project MAY John Sevier Boy Scouts of America Julian U. Stein AAHPERD John Sullivan Friendship Facilities Resource: Dorothy McCahy, Girl Scouts of the U.S.A. Karen Meyer, Office of Senior Citizens/Handicapped Camille Vogel, Horizons for the Blind Larry Wallingford, Office of Senior Citizens/Handicapped
4:15 p.m. - 5:00 p.m.	Tower Salons	Myths and Reality Panel: Julian U. Stein, AAHPERD, Moderator Carl B. Eichstaedt, Illinois State University Joan Kristoll, United Cerebral Palsy John Sullivan, Friendship Facilities
5:00 p.m. - 6:00 p.m.	Penthouse	Project ALIVE (Active Life Involves Vigorous Exercise) Video Tape - An overview of physical activity program for older adults Helen M. Heitmann, University of Illinois, Chicago Circle
6:00 p.m.	Penthouse Ballroom	Reception - no host
		SESSION II
6:30 p.m. - 8:30 p.m.	Penthouse Ballroom	Dinner The Bridge to the Community Henry B. Betts, Rehabilitation Institute of Chicago Preview The Invisible Children A film featuring Gary Burghoff and The Kids on the Block

February 10, 1981 - Tuesday	ROOM	SESSION III
8:30 a.m. - 9:20 a.m.	Tower Salons C & D	Making It Work With Your Resources John Sullivan, Friendship Facilities
9:30 a.m. - 10:20 a.m.	Tower Salons C & D B-1, B-2, G-2	Mainstreaming: A Guide to Developing a Program (Manual II) Small group discussion
		Facilitators Daryl D. Jenkins, Project MAY John Sevier, Boy Scouts of America Julian U. Stein, AAHPERD John Sullivan, Friendship Facilities
		Resource Dorothy McCahy, Girl Scouts of the U.S.A. Karen Meyer, Office of Sr. Citizens/Handicapped Camille Vogel, Horizons for the Blind Larry Wallingford, Office of Senior Citizens/Handicapped
10:20 a.m. - 10:25 a.m.		Break
10:45 a.m. - 11:45 a.m.	Tower Salons C & D	Model Systems: Mainstreaming William P. McCahill, Boy Scouts of America, Moderator Dennis Breitholtz, Little City Patricia Condon, Chicago Park District Vicki Conley, Access Living Stuart Mace, National Easter Seal Society John Sullivan, Boy Scouts of America
Noon - 1:45 p.m.	Penthouse Ballroom	Luncheon Health, Fitness, Age: Keys to Mainstreaming Everett L. Smith, University of Wisconsin
		SESSION IV
2:15 p.m. - 3:45 p.m.		Demonstrations - Concurrent
	Tower Salons C & D	Youth Session Ray Newman, Leaning Tower YMCA

February 10, 1981 - Tuesday	ROOM	SESSION IV (Cont'd)
2:15 p.m. - 3:45 p.m.	Penthouse	Older Adult Session Richard Escutia, Metropolitan Board YMCA Dorothy A. Koelling, Lattof YMCA James Schommer, YMCA of Metropolitan Madison, Wisconsin Everett L. Smith, University of Wisconsin Neil Sol, George Williams College
	Pool	Aquatic Session Mel Balonick, Leaning Tower YMCA Lew Malter, Leaning Tower YMCA Happy Reiss, Leaning Tower YMCA
3:45 p.m. - 4:00 p.m.		Break
4:00 p.m. - 5:00 p.m.	Tower Salons C & D	Including Volunteers in Your Plan Panel: Beth Broadway, Metropolitan Board YMCA, Moderator James Donovan, Metropolitan Board YMCA Pamela Ransom, Hull House Mary Louise Thomson, Voluntary Action Center Resource Mel Balonick, Leaning Tower YMCA Richard Escutia, Metropolitan Board YMCA Dorothy A. Koelling, Lattof YMCA Lew Malter, Leaning Tower YMCA Ray Newman, Leaning Tower YMCA Happy Reiss, Leaning Tower YMCA James Schommer, YMCA of Metropolitan Madison, Wisconsin Everett L. Smith, University of Wisconsin Neil Sol, George Williams College
5:00 p.m. - 7:00 p.m.	Tower Salons C & D	The Inclusive Mainstreaming Reception Poster sharing, exhibits and A.V. previews Lew Malter, Leaning Tower YMCA Coordinator

ENJOY A LEISURELY DINNER ON YOUR OWN

February 11, 1981 - Wednesday	ROOM	SESSION V
8:30 a.m. - 9:45 a.m.	Tower Salons C & D	Evolving the Volunteer Role Joseph Agnello, Voluntary Action Center Beth Broadway, Metropolitan Board YMCA
9:45 a.m. - 10:20 a.m.	Tower Salons C & D	A Unique Opportunity for Your Seniors James M. Liston, Illinois Governor's Council on Fitness and Health
10:20 a.m. - 10:30 a.m.		Break
10:30 a.m. - 11:45 a.m.	Tower Salons C & D	Presentation Developing Independent Life Styles John Sullivan, Friendship Facilities Respondents: Dorothy A. Koelling, Lattof YMCA William P. McCahill, Boy Scouts of America Janet Pagan, Access Living
12:00 Noon - 2:00 p.m.	Penthouse Ballroom	Luncheon Quo Vadis William P. McCahill, Boy Scouts of America

AUG 26th 1818

STATE OF ILLINOIS
OFFICE OF THE GOVERNOR
SPRINGFIELD 62706

JAMES R. THOMPSON
GOVERNOR

Welcome to the Land of Lincoln:

Your organizations represent concern for others, dedication and service. I wish you success in realizing your goal on behalf of handicapped youth.

Project Mainstreaming Activities for Youth is filling a real need in America today by bringing national youth service organizations and resource groups together. I am sure all those attending your Project MAY Conference in February 1981 will benefit from the sharing of ideas, problems and solutions.

Your efforts will build the bridges necessary to eliminate the problems of our "invisible children." Thanks to all of you for your work. Best wishes for your future endeavors.

Sincerely,

James R. Thompson
GOVERNOR

OFFICE OF THE MAYOR
CITY OF CHICAGO

JANE M. BYRNE
MAYOR

PROCLAMATION

WHEREAS, the Project MAY regional conference will be held in Chicago February 9-11; and

WHEREAS, the conference is a collaborative effort of youth serving agencies to plan, promote and implement the inclusion of handicapped young people into regular programs; and

WHEREAS, in addition to addressing the concerns of handicapped youth, the conference will consider the situation of older adults; and

WHEREAS, the conference will be held at the Ramada O'Hare Inn in Des Plaines, with Executive Director Grace Reynolds in charge:

NOW, THEREFORE, I, Jane M. Byrne, Mayor of the City of Chicago, do hereby proclaim February 9-11, 1981, to be PROJECT MAY DAYS IN CHICAGO and urge all citizens to take notice of the special events arranged for this time.

Dated this 21st day of January, 1981.

Jane M. Byrne
Mayor

INCLUSIVE MAINSTREAMING

by

Julian U. Stein
American Alliance for Health, Physical Education,
Recreation and Dance (AAHPERD)

As we delve into the topic Inclusive Mainstreaming, let me ask you to think about several things:

- How many of you think of Venus De Milo as a double-arm amputee?
- How do you respond to a Canadian poster which has a young man in a wheelchair with a caption that simply says, "If you look long enough, the wheel chair will disappear"?
- Do you ever ask yourself, "Why am I interested, why am I involved in working with and for individuals with handicapping conditions?"

It is necessary for each of us to reflect on our own personal motivations. In reflecting upon personal motivations, we will find many answers in directions and things we do. Dolly McGlone, who retired from the Denver public schools at the age of 65 and then went to Laradon Hall, a school for moderately and lower level retarded, where he worked until his death, raised a very pertinent question when he was in his 80s. His question was, "What is the problem with mentally retarded? Is it their inability to learn or our inability to reach and teach them?"

In a film dealing with learning disabilities, a young man from Arizona is shown receiving his high school diploma. His counselor is an overvoice as the boy receives his high school diploma simply states, "If he can't learn the way you teach, then you had better start teaching the way that he can learn!" How do you react to the statement that many individuals have impairments or disabilities, but society creates handicaps? How much of what has become needed and necessary from perspectives of professional providers of services has become necessary because of the very conditions those with handicapping conditions say society has created? How much of a Catch 22 do we find ourselves? We create handicaps through attitude, and then salve those attitudes by providing services that we perceive are needed!

Are services needed in terms of individuals for whom services are designed? How were those with handicapping conditions dealt with in the past? First these individuals were categorically labeled.

> "There are labels in my shirts. They tell me front from back. My PF flyers make me run faster on the track. Billy the Kid made my pants and Bonnie Doone my socks. Mama says Mattel made my brightly colored blocks. There are labels on most all my things and that is plain to see, but mama, why is there a label on me?"

After being labeled in terms of categorical handicapping conditions, they were grouped for programs and placed into activities based on those handicapping conditions; something went on in those programs, but how much of it was education?

Many times what went on in those programs was not consistent with interests, needs, and abilities of those for whom programs were being conducted.

In physical education and in recreation this same pattern was evident. Many people look upon current emphasis in physical education, physical activities, and sports for those with handicapping conditions as something new. Adapted physical education has been on accreditation standards for public schools and colleges and universities since the mid 1950's. If you look at what went on in many of those programs, all of us would be both embarrassed and ashamed! What went on in these programs many times consisted of little more than rubber horseshoes, ring quoits, chess, checkers, and shuffleboard activities physical educators thought were limits of which these individuals should and could participate. No wonder there was resistance, reluctance, and even belligerence at these programs. We see this particularly when looking at what individuals with handicapping conditions are accomplishing in the physical and recreational areas.

How many of you are aware that five individuals in wheelchairs finished ahead of Bill Rogers in the 1980 Boston Marathon? One of these individuals completed the course in one hour and fifty-five minutes, almost 15 minutes ahead of Bill Rogers! This means his time for 26 miles, 385 yards in a wheelchair, was an average of 4 minutes 22.8 seconds per mile--how many of us in this room can come close to running one mile in 4 minutes, 22.8 seconds, much less put 26 of them together?

In Toronto, in 1976, at the Olympiad for the Physically Disabled, a young Canadian, 18 years of age, single leg amputee with no prosthetic devices or aids whatsoever, high jumped 6 feet 1½ inches. In the next six months he increased that jump to 6'4½". Today he is high jumping 6'9½" and people in Canada feel that 7 feet is not out of the realm of possibility for him!

These same levels of excellence can be found in all areas, particularly in activity areas of organizations each of us represents. Today, emphasis should not be upon label, place, and program, but rather in determining what are abilities, what are interests, what are needs of the individual, and then develop program approaches so that individuals can participate in such activities. Included in this process is appropriate placement in the most integrated setting possible, the least restrictive environment as The Education for All Handicapped Children Act calls it. Programs should be conducted in the most normal settings feasible. The responsibility is ours; right to participate in those programs is theirs.

A parallel to American law can be made. In American law an individual is innocent until proven guilty. We have condemned individuals with handicapping conditions as guilty until they proved their innocence. In the past they were relegated to special programs, and had to earn their ways out. Unfortunately in too many cases they did not ever get out. This was not because of what they did or didn't do, but because of our preconceived ideas, our hardened categories. Emphasis was upon what individuals with handicapping conditions couldn't do. If an individual was successful, then he/she was an exception, not the rule. We did anything so that our points of view remained unchanged. Today legally--and this is the only time I am going to mention legally because I don't think that should be our approach--individuals with the handicapping condition are innocent and it is our responsibility to prove their guilt! The individual has the right to participate in regular programs. If such placement is not appropriate, then it is our responsibility to show why and to program so that this individual is in as close to a regular setting or normal environment as possible.

Emphasis on least restrictive environment, most normal setting, most integrated setting, does not mean doing away with special programs. It also does not mean indiscriminately and arbitrarily putting every individual with a handicapping condition into a regular program. Dumping is occurring, particularly in public schools. Placement decisions must be made not on the basis of handicapping condition, not categorically, but rather in terms of each individual, his/her interests, needs, and abilities as well as disabilities. Some individuals who diagnostically appear to be very very similar often have very different needs; some of these individuals can be integrated right now. Other of these individuals may need segregated, separated programs. Determination of which--integrated or segregated--is based on the individual.

In the past programming has been either/or. Either an individual was integrated into regular programs or separated into special programs. No longer can we function with a dichotomy of integrated or separated programs. These are the extremes; in between are many steps that link the two extremes--part time regular placement, part time special placement, resource room approaches, classes, alternate placements. Accommodations must be made in regular placements so individuals can participate actively in least restrictive environments. Perhaps buddy systems could be used. Reinforcement may be needed. We could spend much time discussing these approaches. However I know specifics of implementation will be dealt with during the course of the next two and one-half days.

As we look at individuals, we need to consider a number of other factors to insure appropriate integration into regular programs. We must involve the individual in the decision making process. We must not impose what we think, but must work with and get input from individuals with handicapping conditions. Then we can guide, provide direction and assistance, and with some individuals, regardless of type or severity of handicapping conditions, see that they take part in regular programs. Many of these individuals need no modifications, no accommodations to take part successfully, safely, and with personal satisfaction with their able-bodied peers. Because an individual does not have use of arms, has to use or hold a paintbrush, charcoal, or pen for India ink drawings in the mouth rather than in the hand, does not mean that individual needs a special program. Because an individual holds implements in the teeth does not mean that he/she should be relegated to a special program. Specialness in art programs need to be based on art ability--or lack of it--not on handicapping condition. Specialness in music programs, physical activities, aquatics, recreation, camping, drama, sports should also be based on abilities of participants.

A young lady who at the time of an unfortunate accident had been participating in a recreation department program. She lost one leg. After trauma subsided and successful rehabilitation she went back to the recreation department and said, "Well, I'm ready to go back into the program."

Personnel at the recreation department said, "The program for you is on Saturday morning at 9:00 a.m."

She said, "What do you mean the program for me is at 9:00 a.m. on Saturday morning? I was in this program before and am ready to go back into it."

People from the recreation department said, "But the program on Saturday is for our amputees!"

There was no reason that she could not and should not have gone back to the same program that she had been in before she lost her leg.

A severely involved individual with cerebral palsy in the Dallas (Texas) area put it very pointedly when he said, "A difference is a difference only when it makes a difference!" How many of the differences we are using to relegate individuals to special programs and keep them out of regular programs are artificial differences we have created? Many individuals with handicapping conditions can take part in regular programs with various simple accommodations.

Let me use two or three examples. Suppose you have a bowling program--instructional, recreational, competitive, makes no difference--and a blind person wants to participate in that program. Accommodations that this blind person can use might be a bowling rail, a device that helps the individual orient to the lane. Many blind--even deaf-blind--individuals do not use bowling rails; they orient on the basis of a ball return, a post, or simply have someone indicate verbally where they should line up for their starting positions after which they make adjustments themselves. If bowling ability is comparable for the league--again whether recreational, instructional, or competitive--use of a bowling rail enables a visually impaired individual to participate in that program.

In the same bowling program may be an individual with cerebral palsy or someone with an arthritic condition of hands and fingers, or a person with missing fingers or another individual with insufficient muscular strength and endurance to handle conventional bowling balls. These individuals can use special handle bowling balls. The handle comes out; it is on a strong spring so that when the handle is released the spring pulls the handle back into the ball so that there is a true roll and the user can take part in regular bowling programs.

Suppose individuals who are severely paraplegic or quadraplegic want to participate in this same bowling program. Bowling ramps can be used. Bowling ramps are not only made of different materials, but constructed so that individuals can initiate movement of the ball with various parts of the body--hands, elbows, feet, or while sitting on the floor. We know of one individual in Atlanta who initiates movement of the ball down a bowling ramp with his tongue--and he participates in regular bowling programs.

Individuals with missing limbs who are post-polio or paraplegics, ski downhill by using outriggers, poles with small skis on ends of the poles. This works just like training wheels on a two-wheel bicycle. The individual has the ski or skis with the two outriggers for added support. Often, when skiing in a straight line, neither outrigger touches the slope--total balance is maintained on one ski. If needed, skiers can use both outriggers while often they only maintain two points of contact--the ski and an outrigger. We think nothing of using training wheels on a two-wheel bicycle so why give any more thought to an individual with mobility problems who uses outriggers when skiing. There is no reason users of outriggers can not be instructed in ski programs with able-bodied persons. Many individuals right now--today--can safely, successfully, and with personal satisfaction, take part in various activities with or without accommodations. These individuals have the rights and we as providers of services have responsibilities to incorporate and include them in regular programs.

But what about individuals who cannot today safely, successfully, and with personal satisfaction take part in regular programs and activities. They may need the security of smaller, more segregated programs to develop confidence, enhance skill, further ability, foster emotional stability, create social awareness, and possibly sharpen intellectual aspects of the activity or related to the activity. This becomes the half-way house type program to build a bridge to the regular program. These should be transitional programs and temporary placements so that each individual can become a part of the mainstream of society as quickly as possible. This is an example where early intervention is so important to young children--help them develop communication and develop the foundation that enables them to be integrated at earlier ages. The more we as individuals associate with that and are involved with persons possessing handicapping conditions, the more reasons for accepting or rejecting them are exactly the same as for accepting or rejecting anyone else.

Members of another group who cannot today safely, successfully, or with personal satisfaction take part in regular programs and activities include severely, multiply involved who are going to need longer range, special, separate and segregated programs. Notice, the term is long range not permanent. When we say permanent, our hardened categories indicate that we never expect these individuals to develop the abilities to be integrated into regular programs or activities. All of this is part of a continuum of alternative placements based on individual needs. The goal should be to move and help individuals move through that continuum to integrated settings just as quickly as possible.

In all program areas--education, recreation, service--we lean to homogeneous groupings. Is this really for the benefit of participants or an approach that makes organization and administration of programs easier? Some of you may have seen a television program called Larry. This true story is about a young man who was diagnostically severely and profoundly retarded. He had been in a residential facility since one week of age. A young psychologist saw in Larry reactions which indicated to her that Larry was not as retarded as diagnoses showed, so she began to work with him. Larry was not verbal, had no animation in his expression, and not only walked in an uncoordinated way but possessed a limp. As it turned out Larry was not as retarded as he had been diagnosed--he was not retarded at all! He lost his limp, walked in a very coordinated way, got a great deal of animation in his expression, and became very,very verbal! What brought about these changes? As Larry progressed he was taken out of the residential facility environment and into the community. At the residential facility he only saw individuals with similar behavioral manifestations as his own--had no positive models, only negative behavioral models. As Larry ventured into the community, he did have problems. Although rolled, beaten up, taken advantage of, he felt these parts of life. In talking with the psychologist Larry pointed to individuals in the ward and said, "This is a waste of their lives." He felt they too should be in the community having the same benefits as he in associating with persons without handicapping conditions, opportunities to see and interact with individuals having a variety of behavioral characteristics.

What is intended by normalization is reflected in Larry's story. Normalization does not mean to make normal. Normalization means to provide the opportunities to experience as normal life style or life rhythm as possible, ways it is expressed in the Scandinavian countries. Normalization insures that individuals do not have meals--meal after meal--with two hundred others, do not live in a unisexual world, do not do everything in one room, are not isolated in a single environment. Normalization enables all individuals, including the most severely and multiply involved, to experience a normal life cycle of getting up in the morning; going to work, school, sheltered workshop or special school; having recreational opportunities in a variety of settings; interacting with both sexes; and being active in many settings. This is what normalization is all about. Normalization promises a life style that lets an individual truly be a part of, not a part from, the mainstream of society.

Another important factor in this entire integration process demands greater involvement of individuals with handicapping conditions. Too often the decisions are made for those with handicapping conditions by able-bodied individuals. Individuals with handicapping conditions asked to be involved, then they demanded to be involved; when we continually did not listen, they gained the legal right to be involved. For a number of years I have encouraged groups to involve a minimum of 51 percent of those with handicapping conditions at decision and policy making levels so that those so intimately affected by these decisions and policies will have control over their own destinies.. Great strides that have been made, despite efforts of many able-bodied individuals, would not have been possible in enacting Section 504 of the Rehabilitation Act had it not been for the militancy of individuals with handicapping conditions.

As we look at integration, many individual providers of services feel threatened. Specialists are concerned about a large majority of persons with handicapping conditions being integrated into regular programs so that they are asking. "What am I going to do professionally?" Instead they should be looking at how these changes create new needs and different demands for the background, expertise of specialists. As early as 1975 the General Accounting Office dealt with these changes in a report relative to implementing certain approaches of what was incorporated into The Education For All Handicapped Children Act. Even the GAO recommended a resource role for specialists. In such roles specialists serve as resources to community agencies and schools to provide support and assistance to regular teachers and leaders in community programs. Emphases are in helping each better understand and incorporate individuals with handicapping conditions into their regular program along with some nitty-gritty practical how-to-do-it assistance.

An individual teacher or leader may have a great attitude toward accepting those with handicapping conditions into their programs. However, when he/she finds that on Monday a totally blind participant is to enter the program, anxiety and apprehension take over. He/she has never dealt with a totally blind individual. This is where the resource is needed, he/she can be called upon to help in integrating this individual, show how to organize programs, team teach/lead with the teacher/leader, demonstrate teach/lead, help get adapted devices that might be appropriate, get professional materials to help in this process, get materials which the participant can use conducting service activities, serve as the type of support that is intended. When most individuals receive this support they are much, much more receptive to incorporate participants with handicapping conditions into their program.

In an ancient culture that in many ways was no different from today, the younger generation was always trying to show up the older generation. In a particular tribe there was the wisest of men that a group of the younger generation wanted to show was not quite so wise. So they devised a plan. One young man would catch a bird, go to the wise man in front of the rest of the tribe, tell him that in his hand was a bird, and it was up to the wise man to say whether the bird was alive or dead. If the wise man said the bird was alive, the bird would be crushed and the dead bird shown to everyone. If, on the other hand, the wise man said the bird was dead, the hand would be opened to allow the live bird to fly away. So they went to the wise man and the young man said, "In my hand I have a bird; tell me is the bird alive or dead?" After a very few minutes of thought the wise man said, "The answer to that, my son, is in your hands!"

The degree to which individuals with handicapping conditions are truly integrated into programs and become a part of, not a part from, the mainstream of society, is in your hands.

MYTHS AND REALITIES

by

Carl Eichstaedt
Illinois State University

I am going to start by reading two very brief quotes because they both relate to the topic which is "Myths and Realities of Mainstreaming."

"Reflections of Mainstreams"

> "It occurs to us that mainstreams do not necessarily run a smooth, tranquil, straight course across the landscape. Mainstreams may follow a twisting, winding, or even tortuous route. They may have eddies, whirlpools, rapids, falls, dams and dikes and you can never tell what you will find in the bullrushes. The stream itself will not get the children where they need to go. It also takes the craft best suited to each individual's plotted course with pilots equipped to aid, to avoid the shoals and unnavigable currents, to prevent them from coming to harm or from drifting aimlessly into the pounding surf of the sea of life."
>
> "If our society and its resources can help a quadraplegic operate a wheelchair by the breath from his or her mouth, if a severely retarded person with special training can outproduce a non-handicapped person on an assembly line, if an epileptic young girl can set a new record for long distance running, then our society can use its resources to change itself."

In talking about normalization and mainstreaming, remember mainstreaming is merely a term that came in before Public Law 94.142 and that now we talk about the least restrictive environment for individuals. We talk about all children being placed in a more effective place to learn. I think that this is a critical issue that we continually look at because regardless of the fact, if a youngster is considered to have a disability or an impairment or a handicap, he fits into a very common kind of grouping just as many times we would find with normal individuals who are low skilled. The youngsters who have trouble overcoming their fear of water, who have trouble mixing with other children, who have trouble meeting and going other places, these are the very same basic fears or indecisions that most children will have.

I would like to, for example, put you into a situation. I will be a swimming teacher and, having taught swimming for a bit, you can appreciate this. Mother comes in with the child, says, "He can't swim. He is nine years old and he is afraid of the water."

Myths and Realities

Obviously, what you do is take the youngster by the hand, tell Mom to go away somewhere else, take the child down to the deep end and push him in. He bubbles to the top. He comes up, grabs ahold of the side. You pick him up and you say, "Can you swim?" "No, I - I - I - No," turn him around again, push him in again.

Isn't that the way to learn to swim? My dad taught me to swim. He said, "Damn it, swim," and I swam. What about this youngster? As I reach in the second time to get him, you know what he is going to be like. He is going to pull back. Tears may be in his eyes. He is so frightened he doesn't know what to say, scream or cry. He may even be kicking. Wouldn't it have been a better situation to have taken the child down to the shallow end and then get into the water with him? You could let the youngster stand on the bottom and then progress very slowly. Take him along, teach him how to look at the water, how to blow bubbles, how to wipe water out of the eyes, and before very long you have that youngster looking under the water, opening his eyes. You say, "Now hold your breath under water. Just put your face in, don't put all your ears in. I want to see how fast you can do it. 1, 2, 3, 4, 5, 6, 7. Good, you did a good job on that."

You bring the child along according to what he brings with him. We are not going to frighten that youngster. We are truly going to bring something along to make him enjoy it. I think that is the number one critical issue of any person we have worked with whether he is impaired, disabled, handicapped or normal. We are then going to make that person feel comfortable in the environment. The child should be put in the position where he will learn fastest.

I truly believe that the swimming people, the people who have planned for years and years and years, have the total idea or concept for teaching under control because, under any good program, what do we see? We see stations. We see a beginner and we see an advanced beginner. We see different areas. Yet that same physical educator who will break groups down into ability groupings in the swimming pool; when he puts that same group into volleyball, what does he do? He teaches all the children the same things in spite of the different abilities he is faced with.

We tend to forget that ability is the crux, is the most important and critical issue. We have to take a look at what the child brings with him. Let us not just talk to the child. Let us not talk about a handicapped child. Let us talk about the child. What does he bring with him? What level of ability does he have? At what level is he functioning? Does he have certain problems that he may bring with him?

What about the spina bifida child? The number one concern of all spina bifida people is, "I am going to be embarrassed because of the chance of being incontinent. I may not be able to control my bowels and I may not be able to control my bladder. I don't want to be with people." Is it right to shove that individual into the class with normal children and say, "Go in because it is good for you?"

We know better than that. We know that we have to take that individual and we have to progress with that youngster to make him feel comfortable in his environment. Once we bring him that comfort, that feeling of being at ease, then we can start to teach because at no time are we ever going to come across and force things down a child's mouth.

Myths and Realities

You cannot convince a child to eat liver because it is good for him. You have to be very subtle. You cannot bribe a child or force him to eat the liver. It is the same with a handicapped child. We cannot force him to get into the pool, but we can make him feel comfortable about using the pool. Perhaps he has to play with a bucket of water to get used to the water. Perhaps he should be given a wet sponge to wring out and put on his head. Do this over and over. Let him put the sponge on the teacher's head and wring it out. The child can be taught how to wipe his eyes. We want him to be comfortable. One thing we don't want to do and that is to dump a child into a regular program if he is not ready. That is the worst thing that we could do.

For years we have been under the concept that we wanted to help these children in special ways, give them special teachers, special help, special consideration because that is what they needed to learn. We run into a major problem of trying to put everybody into little pigeon holes. We really need to look at what the children need and then decide how we can help each youngster most effectively. Should he be with a group or should he be worked with on a one to one basis? It may be one way or it may be another.

One of the best things that is happening with 94.142 is that we can take a totally blind youngster and put him into a swimming pool. We don't put him into a special class because that child can learn as well as anyone else. If we have a unit in our program that is cross country, where children can learn to run, enjoy running and jogging, what do we do with a blind child? Do we let him run? Yes, we do. We put him on the arm of another individual and away they go. He is going to experience all the joys that any other child will, with the help of his buddy.

We learn to look at a child to see how many activities he can truly be put into with very little modification. If the youngster, in turn, has special needs and they can't be met in the regular class, that child is in the wrong class. That child should be put into a more individualized program where we can reinforce those basic skills that he needs for him to be able to learn. We can't learn by the whole myriad, the whole world of the psychomotor, the world of physical. We cannot do it all for all children, but we have to be able to isolate what is the most important thing that that youngster needs, what is the second most. We must prioritize those particular needs and then bombard them in the most effective way. We can put him into the regular program with the regular children as often as we possibly can for his benefit because every program will be based on his needs.

Some day....I project this and the other day I got shot down for it because I said in the year 2000 all youngsters will have individualized educational programs as we are developing now for special education. Someone said, "You're late. We are going to have that before the year 2000." I truly believe it.

We are on the right track when we first take a look at the child. He is the one who dictates the program. He is the one who dictates the number of teachers. He is the one who dictates how large the class is. He is the one who dictates the amount of equipment needed or the facility. That child is then going to be the most important thing. We are no longer going to look at sixteen-year-old boys and girls in the class. We are going to look at Bobby and Billy, Susy and Betty. That is when education is going to be totally,

totally exciting. We often worry about mainstreaming because a child will automatically be put into a most appropriate place to learn. I say we are on the right track.

At this particular point I would like to read one little thing just to wrap things up. This is about a severely involved cerebral palsied, mentally handicapped young man. It was a quote that came out of the "Bethesda", a little periodical that comes out that tells about the Bethesda Lutheran Home. It is a quote from this young man. He said,

> "I used to stand and sit in a wheelchair using the rail in the pool to learn to swim. I used the life preserver, then I used an air collar around my neck. Now I can swim without the collar, with my hands in the air. I can swim on my back without anything to keep me floating. I kick my legs and use my back to swim. I hold onto the rails and push back and forth with both hands to turn circles and to swim in a straight line. I swing my left hand over my head to swim. At first I was afraid of the water, but I was standing up and sitting down in the wheelchair. I was not afraid when I started using the life preserver. When I used the collar, which I liked so, I used it so water wouldn't get in my ear. I was afraid to swim without the collar at first, but not now. Now that I know how to swim, I enjoy the water."

Is anything ever written about all those particular techniques? For that particular individual no other program was adapted to meet that individual's needs by people who are totally concerned with providing them with the proper techniques, the proper enjoyment. What are we all about? We want to enjoy our lives. That's it. What is our whole goal in providing activities for swimming? In this particular case it is for people, so they will enjoy swimming and being around the water. It is not just to learn strokes, not just for total safety. That is great, but it is also important for them to enjoy being able, in their free time, in their leisure time, to say, "I am going down to the pool. I am going to be able to swim. I am going to be able to enjoy my free time." If we do not instill that desire in these people, we have missed the boat.

Comment: Just two quick comments on Carl Eichstaedt's point regarding when the individual is ready. Do not fall into the trap of projecting that an individual is not ready when it is our perception that the individual is truly ready. Second, we must follow up. We must really believe that the child, rather than the program, must be the center. We cannot individualize if we do not know the individual.

MYTHS & REALITIES

by

Joan Kristall
United Cerebral Palsy

I'll give you just a moment to look over the handouts. The first handout gives you the principle of normalization. How many of you have heard of the concept of normalization? This concept, I think, can be applied to what we are trying to do in integrating and perhaps use in the youth serving agencies, existing youth serving agencies, although the article addresses itself once again to the housing issues.

I am sure all of us on the panel will talk about different myths and different realities. These myths and realities are close to my experience. I am sure all of you in the audience have, in your own minds, your own sense of myths and realities.

The concept of normalization was begun in Sweden, but was brought to the United States by a man named Wolf Wofensberger. The second paragraph of the handout says it quite well:

> "The use of methods and settings which are valued and familiar to offer each person like conditions and opportunities which are at least as good as those of the average citizen and as much as possible to enhance and support each person's behavior, status and reputation."

What this means is that all of us enjoy certain experiences that are growth producing and enhance our lives and if they were taken away from us, our life would be less in some sense than it is as it exists today.

I know that I am priviledged to live in a place that I call "home." Persons with disabilities are not priviledged to live in a place that is really a home as we know it. Many of us experience recreational and leisure time activities. These opportunities are limited to people who have physical disabilities, mental disabilities and mental illnesses.

The concept of normalization really addresses itself to us folks. It says that people who have handicaps are folks too and that they have the right to participate in all the things in life that we enjoy. That does not happen most of the time. The concept of normalization is saying to us, the average citizens of America, what kinds of things do we do? Where do we live? Where do we work? Where do we recreate? Where do the handicapped people live? Where do they recreate? Where do they enjoy things that we might enjoy? What is the difference between the two and how can we mainstream? How can we bring the two groups closer together?

As I was coming here today, I passed a nice house, a house on a typical street. That house had a sign on it, a huge sign that said, "Home for the Elderly." I wondered why there had to be a sign saying, "Home for the Elderly"? What does that sign say to all of us that pass that house? What does that sign say to the people who live in that house? It is just that difference, I guess, that disturbs me when I see "Home for the Elderly" or "Home for the Physically Handicapped." Here again labeling occurs. How do people inside feel about living in a house that is labeled?

MYTHS & REALITIES

by

John Sullivan
Friendship Facilities

We are at the door of history because history for the handicapped is very, very long and the actuality of physical accessibility and the partnership of the able bodied and the handicapped is just a few years old. We are on a great experiment and we are very excited because we can venture and cause different things to happen that could not have happened twenty years ago.

I want to tell a story about something that happened to us two years ago with a client. We had a sheltered workshop as part of our facilities. The client's name was Frank Belnap. He was a 72-year-old trainable mentally retarded. His sister passed away and left him quite a few hundreds of thousands of dollars. When we heard this, we decided Frank should take a vacation to Hawaii. He is a very alert man and a very pleasant man to be with, but no one wanted to take him. The Conservator, the attorney and the bank did not want to have him go on vacation because he was mentally retarded. At 71 years old, to build a bigger tombstone for Frank Belnap was rather ridiculous so we went to the people concerned with the estate and we said, "We want this man to go to Hawaii, but he is not capable of fending for himself. One of the staff from the Friendship Facility will go along with him." This was fine provided we did this and did that. Eventually it wound up in court and the judge said, "The fact that he is mentally retarded and the fact that you people are denying him a vacation is not conducive." The judge decided that the money was his to use for a vacation. Frank went to Hawaii with a staff member of Friendship Facilities. Every staff member was fighting the next year when he went to Jamaica. This year he is going to go to Egypt. Do I have takers?

I would like to talk about a couple of things, first of all exploring. Our exploring program is very very successful. It is so successful that it is amazing. We have mini bikes, we have canoes, we have runabouts. Everybody has flown either in a seaplane or a helicopter.

People ask where we get the money. We get the money from putting on puppet shows and spaghetti dinners. Someone mentioned crushing aluminum cans and we do this. We saved $3,000 and bought several canoes. We go down the Fox River for our canoe trips.

If you use this kind of program, I don't think you can go wrong. First of all you base your structure on a quarterly program. You use indoor, outdoor, social service, vocational and a highlight. We cannot mainstream people without adequate preparation. We cannot just pick them up and send them to Orlando or to Disneyland, or Sea World, or any other place without adequate preparation.

Participant: Somebody may not know how to bounce the ball, but you really don't think about that.

Participant: I am from the YMCA too. I have been working in the field of aging for maybe the last 10 years. We are just now shifting some of our roles. From what I have seen happen in the field of aging, I'm thinking has to happen here and that is to bring together those agencies that are in particular communities who have some common concerns. The Girl Scouts, Boy Scouts, YMCAs and YWCAs have to make a concerted effort to bring people together. It just doesn't happen. I think that one of the things that could come out of this, as far as those of us who are right in the city of Chicago are concerned, is that we have now begun to know some names and faces and tied them into some of the agencies. If the people stay there for awhile, maybe we will be able to get to the next step where we can do some planning together. This is one of the things that has to happen. I really think we should try to bring the recreational agencies together this way. Maybe some of the other agencies are, but I've seen us needing to come together more often.

I worked with the Mayor's Office for Senior Citizens and Handicapped two years ago in the Hall of Fame. A girl who had won awards for skiing had one leg. She said to me, "You people (meaning the YMCA) built your swimming pools down in the basement. You closed us out." Now our new buildings and our new pools are on the first floor, but people didn't think about that years ago. Now the government has made many people and agencies aware of this. We need to begin to do some planning in a smaller geographic area.

Several things have been done relative to that with different groups in the Washington, D.C. area with groups that are concerned with activities. It started as a monthly luncheon meeting to exchange ideas and to build the type of understanding of what each group is doing to set the possibilities for more formal cooperative relationships. Then another thing, and this has been going on for about six or seven years, the therapy groups; occupational therapy, physical therapy, therapeutic recreation, adapted physical education, art therapy, music therapy, as a spinoff from the luncheon meetings began to meet. At the initial meeting, the discussion centered on "should this group remain as an informal unofficial group or should it try to be some sort of official group." Everyone felt that it should remain unofficial, informal, because that way each person could make a decision to attend and participate actively; whereas, if it was formal, it would be necessary to go back through the boards of directors and governing bodies to get permission to even be a part of it. This group has continued on a quarterly basis for seven years and it has done much to promote communication among the groups to remove some of the fears of competition, placing greater emphasis among those representatives in the unique services of each one of the groups. I think this sort of thing can be successful at the community level also.

Participant: I am the State Chairman of the Disabled American Veterans for Scouting for the Handicapped. We are having a seminar in Ottawa on the 7th of March which will give a complete dossier of folders, information and programming. If you want money for your program, I will tell you where to get it. If you want to sponsor a Girl Scout Unit for the Handicapped or if you want to mainstream a Girl Scout Unit, the Disabled American Veterans of the State of Illinois have taken it upon themselves to provide funding through the chapters. They have given me the money to pay your tuition for a week seminar in New Mexico at Philmont Scout Ranch for Scouting for the Handicapped. There you will meet some of the finest leaders in the field, Dr. Nesbitt is one of them. Again, if you are in the state of Illinois and want me to pay for your tuition, it is there. Forget scouting - just for the handicapped.

Participant: I guess I was a little bit troubled when you identified some of the people you work with as trainables, MR's, MI's, etc. I don't even know what those words mean and I don't even know if we need to know what those words mean in terms of individualizing for people. You were saying that in less than twenty years, hopefully we will individualize everybody. I wonder, when we label people what that does to the individual and what that says about the individual. How does that individual feel about being labeled "MR", or whatever. I do not believe those labels are things that we value in our society. I think they are devaluing kinds of things.

Participant: You are asking questions about labels. Without labels we couldn't exist.

Participant: I disagree with that.

Answer: Let me explain this. We have five different programs and the important thing is not that we use the labels, it is how we use the labels. If someone is mentally retarded and cannot read and we have placed 80 people who we were told could not be placed if we did not go to the employer and level with him and say this person cannot read or write, or is developmentally disabled, or he is mentally retarded and he is a trainable; then all of a sudden we are going to lose that person on that job because he cannot read a menu, he cannot do some of the work that would be required. If we level with the employer and say this man is mentally retarded and that we would like to have him working here at the Ramada Inn, for example, then there isn't the repercussion. When you do away with labels, you do away with the truth. It is not the way the labels are, it is the way the labels are used. It is your responsibility to see that the word mentally retarded is not derogatory, but is a positive statement.

Participant: A question that many people raise concerning the Education for All Handicapped Children Act is related to what both Joan Kristoll and John Sullivan are saying. On the one hand to be eligible you have to be identified through a traditional, categorical labeling process. However, the next step, once you have determined eligibility by those criteria, is to forget about them and then look upon the individual's needs. An individual who meets the first criteria in an identifiable handicapping condition, who does not have a special need, is not handicapped by definition under 95-142. There has to be some means of determining eligibility. Current means is by categorical handicapping conditions. However, once that criterion is met for eligibility, then let us forget about it and look at how that condition affects the individual's function, as John said. To me it is not important that the individual is labeled as moderately retarded. The important thing is that the individual cannot read and that then becomes the key, not the fact of the label, for the condition. It is how the condition affects the individual's ability to function in whatever the particular task is.

Myths & Realities

We have indoor programs, anything from roller skating to a glamour panel. At the panel girls sit at a table and the men ask questions about correct behavior and mannerisms.

We also have social programs. There is a disco every Friday night and on special occasions there is a band. The disco is a way of normalization; there are fifty, sixty, seventy people at one of these. As a rule, they can't go to a disco in town. Our disco is teaching them how to learn to cope with normalization or mainstreaming because here they learn how to act and later they will be able to go to the discos down town. They are getting the experience they need.

I had a bad experience with a group of special education boys at a movie. Their actions were atrocious. They threw popcorn, spilled coke and ice on the floor, and also did other unacceptable things. The blame for this lies with their teacher. She had not prepared them. They should have been taught socialization as well as some other things.

We have a blind receptionist who was not taught good manners. It took him two years to learn how to answer the phone correctly. I think perhaps more time should have been spent on mainstreaming than on educational factors.

The next thing we talk about is service. We wash all the windows at the YMCA once every year and we get to swim there. We use the gym there and for this we fold their brochures, sometimes we wash the windows or clean their waterfront. Sometimes we loan them our canoes. Since every explorer group needs a sponsor, the YMCA serves as our sponsor and we do this service for them.

We have a highlight. Our highlight is going to a candlelight theatre to see a musical. This is fantastic. They are mainstreaming, they have dinner with everyone else, they are learning their manners, they are learning how to order, they are able to function.

Two years ago the highlight was a conference at Orlando, Florida. Twenty-one countries came, twenty were invited. People came from Kuwait, Iran, Scotland, Germany, Switzerland and many others. Many of those who came were blind. Of the three-hundred attending, seventy-five were in wheel chairs. We had to plan, not necessarily on mainstreaming, but to develop mainstreaming. The payoff on this is that there is going to be another conference in Orlando this year and even more people plan to come.

Audience Participation

Participant: The statement was made by Carl Eichstaedt that this was the first time that he had realized that while the Y was breaking down skill teaching in swimming activities, it was not being done in other areas. It is a very good example of where we have failed within our programs, especially those of us who have been doing things for years.

Myths & Realities

Now I could go on in this because I have worked out a model to translate it to practical terms. It is very basic and related to something that you probably learned in high school biology and if you didn't learn it in high school biology, you learned it in your first course in psychology. It is called the SR bond with the P in between and how each one of those conditions affects the ability to learn and how it affects one of those phases. Let me start with something that Lynn Burke, who was the 1972 Handicapped Person of the Year of the President's Committee on Employment of the Handicapped, said, "A man with no legs can still achieve great heights, a man with no sight can still have great vision, a man without hands can still grasp, and a man who cannot move can still leap." In essence, what he is saying is that to "Accept me as I am" is the first step in recognizing how the condition affects the task that we are going to be working with.

THE BRIDGE TO THE COMMUNITY

by

John E. Toerge
Rehabilitation Institute of Chicago

I thought we could start by talking about what a Rehabilitationist's point of view of disability is. One of the biggest problems with medical students is that they don't know what it is a rehabilitationist does. What do you do? What is a physicist or somebody in PM & R or rehabilitation medicine? What is that kind of person? Are you really a doctor? Many questions like that are asked so I thought maybe, from our standpoint, it would be a good idea to talk about it. Disability is a relative term as most of you figured by this point in time. Disability can be a disruption in somebody's life for a variety of reasons. We have people with rather overwhelming disabilities. We have people that have trivial disabilities and they may not be exactly what they seem to start with.

We had a man who was in the hospital who used to be sheriff in this area and decided that he would go out and break up a few rowdy youths during a rather hectic time in Chicago's history. He wound up with a broken neck, a quadraplegic. This man's life changed very little because he was somebody who was giving orders on most accounts and he had a group and staff around him to carry out those orders. His life changed very little even though he was faced with quadraplegia.

On the other hand, a gentleman showed up in our outpatient department, waded his way through the wheelchairs, the crutches, the canes, various other things and said, "I feel very strange being here." I asked why. He said, "Because my finger doesn't move." I thought to myself, "You are strange being here. Why would you come to me with this finger." We talked about it a little bit and I said, "Which finger." He said, "This ringer finger on my right hand." I said, "Tell me more." He said, "I am a concert pianist."

His disability was overwhelming, he couldn't go on the concert stage with his finger the way it was. Happily his finger was wonderfully rehabilitated because we do that sort of thing. The point I want to make is that disability is a relative thing at any given state in time.

What is medicine's point of view of disability? It is acute care, acute hospital, booming community hospitals in your area where the ambulance comes wheeling up and they take out a spinal cord injured patient. They take out the patient with the heart attack. They take out the patient with the stroke. That's what medicine understands of disability. The acute end of it, plugging them into IV's, watching the monitors, snatching them from the jaws of death. That is what acute care understands about disability.

The Bridge to the Community

Let's get that same person into the physician's office after he survives. First of all, there are twelve steps out in front of the physician's office. There is a narrow little hallway and doorway to get in. The doctor doesn't want the patient to sneak out without paying. The hallways to the back are very narrow. The doors are very narrow. Somehow a person gets this feeling that it is designed so that we don't have to deal with disabled individuals. It is a very difficult thing for many acute care physicians to deal with chronic problems which are going to show up on the doorstep again and again and again.

Let us change the temper of this a little bit. I grew up in an era where jokes occasionally were funny and occasionally made impressions on you. There is a joke that goes something like this. "Mrs. Smith, Mrs. Smith, can Tommy come out and play?" "Why, you know Tommy doesn't have any arms and legs." "That's o.k., we'll drag him out and use him as second base." I don't know if any of you have ever heard that kind of story before. If you are a little shocked now, I want you to think what your feelings were when I said that. I have a license to say that because I am a Rehabilitationist and it is not the way I view patients. I want you to think what your feeling was. Where was your emotion as the story unfolds. Many of you are probably saying, "Poor Tommy, he couldn't go out and play with the kids." Some of you are saying, "Poor Mrs. Smith because she has to put up with Tommy." Some of you are saying "Those kids are really cruel because they said those things."

Did anybody consider Tommy in any of this? Did anybody ask Tommy what he wanted to do? What about the children? Were they really well intentioned? You all thought, well maybe Tommy is going to be out there and have baseball spikes running over him, but maybe Tommy could be out participating with the rest of the group and could be the tag base for second base and participate at his level of performance. If you think of it in a different light, it is not nearly as harsh a story as it may have seemed to you at the start.

Think about where your emotions were as far as the children were concerned. There are a number of things that you can say in looking at something like this. There is gratification in working toward a potential. People say to me all the time, "What a depressing field, I'd never go into rehabilitation, dealing with all those handicaps and those people." But, I tell you it is gratifying to find someone who is motivated to reach their potential. There are so few of us that ever really do that. Reaching that potential of whatever we really might be is the key. That is what we all strive for. We always fall a little bit short.

So let us go back to the story. Children generally are o.k. They are a little cruel at times. They poke a little fun. They pull and push, but generally they are o.k. They come through. Parents have built in biases. They just make the assumption that if little Tommy doesn't have arms and legs, we really had better protect him. We don't want the other youngsters to make fun of him. We don't want him to get into the mainstream of events.

I tell you the important thing though. The important thing is performance. The key is performance. I was in the amputee clinic with an orthopedic surgeon. He said, "You know, you can really tell when a child has used the prosthesis."

I said, "How?" He said, "Because it is all dented and banged up and it looks horrible. You know the important thing about that? The importance is and the key is performance." You look at those children and what are they doing? They are taking that thing and they are using it. The initial shock is looking and seeing, "Oh my God, a hook on a small child, it is awful", and you just watch them for a few more minutes and it disappears behind the joy on their face in being able to perform and do. The equipment disappears. That is what he was telling me.

In our institution on the 17th floor we have the Northwestern University Prosthetics and Orthopedics Center. Because it is such a long name, they call it NUPOC, as you might imagine. There was a course in talking about congenital amputees as far as the upper extremities are concerned. There was a young football player who was a kicker for the high school team, obviously, because he had a good foot. This was the same boy who used his feet to feed himself and do various other things. They attached these prostheses and they were all wound up in them. He was sitting at about eye level from me. They had gone off to the side to deal with these marvelous prosthetic devices that they had put together for this young man and he was sitting up there without any arms and his shoes were off because that is always a good way for congenital amputees to be because then they can use their feet. I looked up in time to see him drumming with his toes, just about as fast as you could do it with your fingers. I realized this is a good foot and this is a good person to be a kicker on the football team. He certainly isn't going to miss out on any of the things that he wanted to do in his high school career.

Let me tell you discouraging stories about the medical community. Some of you look to the medical community to help you find your way through the problem of disability and to help get the answers for what to do with patients with disabilities. Unfortunately, we come up empty in many regards. We had a resident at the institute who had a friend who was a hemotologist, somebody who studies blood work, in New York. He had an interesting problem in anemia in a C-6 quadraplegic patient. Then he picked up the phone and said, "I have the most interesting problem. I have a C-6 quad that has this, that and the other thing, etc.", and the person he was talking to stopped him and said, "Hey, do him a favor, let him die." It was a minor thing.

We had a respiratory resident that made a fatal mistake. Not a fatal mistake, but an unhappy mistake for him. We were standing in the Spinal Cord Unit and he said to me (Senior Resident), "When you get these patients at the Rehab Institute, really, what do you expect them to do?" The patient he happened to be talking about was a C-7 quadraplegic patient and I started on him and said, "Well, he will probably drive a car, fly an airplane, go out to dinner", right down the line. About fifteen minutes after that we were finished and I do not think he will ever ask the question again. Be careful and look very carefully into the medical community. We have a great deal of learning to do in terms of disability and what it means to the patient. We are hospital oriented, office oriented, and miss out on the community aspects of what happens to those patients once they get back into the real world that you and I live in.

The Bridge to the Community

Let's talk about some misconceptions. Don't get embarrassed if you have some of these misconceptions, they are really rather common. Let me just rattle a few off for you:

1. Obviously, with disabilities, you might get it by contact. You might get it by association. These individuals may contaminate you or pollute you in some way. They obviously should stay with their own kind.
2. What can they do anyway? Don't they always smell a little bit of urine and feces?
3. My child is too sensitive to be exposed to that kind of person.
4. They should all be locked up.
5. If they are in a wheelchair, they probably are mentally off a little bit anyway, don't you think?
6. Then wheelchair sports. Only healthy people should take part in a marathon. Really, isn't that pitiful?
7. Why do we have the International Year of the Disabled Person?

Misconceptions. I hope none of you carry those with you. If you do, reverse them at this point. It is important that you do. These individuals are not going to contaminate you or your family. They are not going to be pitiful people. They want to be people. They want to get back into the flow and ebb of their community.

Here are some concepts I would like to leave with you. Some ideas that you can work on and consider throughout the rest of your program here:

1. Performance. Performance is the key. Performance is the key. Performance is the key. That's the whole essence of what we do in medicine is make individuals perform, whatever the problem is. We just haven't recognized it yet. Remember, equipment is only useful if it is useful. If you attach something to an individual because you think it should work, that does not mean that they are going to use it. All the helping hands in the world will not make any difference if it is a useless piece of equipment.
2. Rehabilitation hospitals do not rehabilitate patients. They say, "This person is strange, he is trying to put himself out of business." What I am saying to you is we can do a certain portion of it. You are talking during dinner. We have a great time in the hospital with diabetics, for instance, because we can control their diet, how much they sleep, how much they exercise, how much fluids they take in, etc. After they go home, we have no control of that so everything goes out of control again. We can not rehabilitate a patient. Getting back to the community, getting back to the mainstream of the events is what rehabilitates the patient. That is the bench mark of the quality of rehabilitative care that patient received.

3. The community provides the substance for productive lives. They allow the individual to flourish or to whither. There is a responsibility out there to allow individuals to reach their own potential.

4. Architecture, architectural and attitudinal barriers provide significant handicaps to individuals. Thirty-five million disabled Americans are in this country in some form or another so everyone in the country will have some contact, at least in an extended way, toward disability. It is important that if you are going to work with disabled individuals, you have to be in touch and understand how you feel about the disabled population.

5. One other thing is tried and true. Familiarity reduces anxiety. The closer you get, the more you do. The more you understand, the less anxious you will be about dealing with that population.

I inherited the title for this talk from Dr. Betts along with the occasion to speak here. He said to talk about the bridges to the community. It is a natural. You can figure it out, it won't be a problem at all. He was right. Bridges to the community in terms of what you are doing are extremely important in a conference such as this.

First of all, you need personnel. You need people to provide guidance to push in the appropriate directions, to know the appropriate people. You need personal involvement, something that triggers you, a wonderful event, a wonderful outcome. Somebody in your own family who is disabled can push you along a little bit and make it your own battle. We need to work for societal adjustment. It's tough, you need to push your way in through the door.

Societal accommodation . We know in learning principles that you do not take on a whole brand new idea at once. You take it on in little bits and pieces. Society has to accommodate slowly to a disabled population. Ultimately, we hope to have societal acceptance of the disabled population and certainly getting individuals back into the mainstream of their own lives.

Who can do all this? Activists can, activists of any variety. Handicapped individuals who are very strong can do this. The blind are probably one of the strongest groups that you will run across. But remember, as an able bodied individual, you have missed much of the essence of what it is like to be disabled. You have to understand, talk and touch those disabled individuals in order to understand. Interest community groups. Obviously these include the YMCA, Boy Scouts, Girl Scouts. I am not going to give you an exhaustive list, Grace Reynolds has already told you who they are. Ultimately you must involve special interest groups. Special interest groups supposedly are dying on the vine with the new administration, but I think there are some that need to be maintained: United Cerebral Palsy, Multiple Sclerosis Societies, organizations for visually and auditorially impaired, and so on right down the line.

How do you do it? You are going to learn the tools that it takes in order to accomplish these tasks. First and foremost is interest. If you have some interest in what is going on, if you have dedication, that is probably one of the most important first steps that you can take. Planning is important as well. A single flare is not going to make the difference. It is planning and conscientious effort to get the goal attained. Development of programs, ways of doing it, people to do it with you, very important. One thing we never do or rarely do, is assess the outcome. What did we do? Did we make impact? Did we have some method of looking at what we have done in order to say it is a good thing or it is a bad thing or we have accomplished the task we have set out to do. I would strongly urge you to look at this end of things. Try and figure out just how, positively or negatively, you have affected the lives of the individuals you care most about.

Finally, we need to arouse public interest. The public has many things in which to be interested. If you have a good reason and you have good commitment and thought, these individuals will be very involved with you. Getting awareness within the public sector is extremely important.

I would like to conclude and say that I am happy to be here. I think you are in on the beginning and breaking ground essentially for a task that is going to be very arduous and long. It is one that is not necessarily a popular cause, but it is a very important issue in terms of the patients that we see. If we do a wonderful job in our mighty fortress that is extremely accessible and then turn individuals back into the community that is not accessible due to attitudes or barriers, we really haven't done them a service. And when we turn around and look at ourselves and say, "We rehabilitated them for what?" Then we know that we really haven't reached out far enough. You, in fact, are providing those bridges into the community for the rehabilitation effort that we start.

MAKING IT WORK WITH YOUR RESOURCES

by

John Sullivan
Superintendent, Friendship Facilities, Ottawa, Illinois

Today I am going to sign up each person here for the Friendship Facilities Club. This club has been in existence for fifteen years. Each one of us will become a member and by the end of the session we will understand the ramifications of the Sons of the Desert. We took the name from a Laurel and Hardy film. The reason we are going to form the Sons of the Desert Club is because there is a need for it. In a small town of 23,000 people like Ottawa, Illinois, the people have to be acclimatized to the mentally retarded, to people who are paralyzed and who may walk down the street with odd gaits. The townspeople have to be oriented and acclimatized to the fact that there are people who will go into a restaurant and not be able to order from a menu because there are no pictures on it. In some towns, unethical merchants sometimes cheat mentally retarded persons who do not know what change they should receive. In a town, which has ingrown prejudices against the physically and mentally handicapped because of fear, because of the unknown, it takes work on a constant basis to achieve a complete turn around.

Today Friendship Village is on everyone's list as the greatest thing in which they have participated. The big secret is that the entire town now participates. Every year there is an International Fair. The townspeople come to the fair. They feel they have contributed. They have built Friendship Village. There is no government money in Friendship Village. We have our membership cards. We know what our need is. We know why we are going to do this. We are doing this to bring people in because there is a need.

Why is there a need? It is because the people we are trying to socialize are not accepted in town, at the discos, in many places, even restaurants. This is because they will go to a restaurant and meet each other and socialize over a cup of coffee for three hours. Often the restaurant gets perturbed. Sometimes these people will go into a restaurant and become angry with each other. All of a sudden each person is sitting alone in a booth. There is no place for other customers. The Manager calls me. I may have to go down and explain why such behavior is not socially acceptable.

Participants. We will talk about the participants who will be in our club. With whom are we going to deal? How many people do we want? What age group do we involve? When do we meet? What leadership and staff will be needed? What criterion are we going to use to form this program?

Advisor. We are going to have an adult advisor. We will have three adult assistants and ten committee persons and one chairperson.

Programs. What are we going to do? If we don't have any program and haven't any structure, what can we accomplish? Yesterday we talked about outdoor, indoor, social service, vocational and other programs. Vocational programming is the most important thing we can do, provided we teach people to socialize first. Most people who come to the facility can pick the oranges from the apples and do not have a difficult time making the decision. But where the decision and where the problem comes in is they cannot relate to each other because they have been hidden away or they have become so shy and so retiring that they cannot, in any way, shape or form go out and be placed on a job and make what we are all after; the good American buck. To the mentally and physically handicapped, making a good salary is a great achievement. No one should ever take the opportunity to work away because work is a normal thing. Work is a good thing, however, we have to adjust them so that they can go and relate to their peer age group wherever they are.

What are we going to do? We are going to have a disco. That disco is going to be able to take people and put them together and let them interact. When I grew up, I fought with my brother and I fought with my sister. My sister and brothers fought with me. Sometimes I won, sometimes I lost, but this is a natural growing up process. You see it with animals where they have combat with each other. Because the mentally retarded and physically handicapped sometimes do not get along with each other, we think it is because they have disabilities rather than the fact that this is normal. But, nevertheless, sometimes it gets out of hand. If it happens in public between two normal people, it is put down as a nuisance. If it happens between people who are handicapped, it is counted as a mark against the handicapped. We want to use the disco and teach them to relate. We have people who can work with people regardless of how obnoxious they are. We want handicapped people to learn how to work with others so they won't return to a Friendship Village except to the discos or other facility functions that we have. This happens. This works. If we just developed work adjustment, it wouldn't have. This is what we are getting at in a basic program as Sons of the Desert.

Activities. We do an enormous amount of traveling. We talk about sports. We talk about non-competitive sports. We base people against standards. That is not to say we don't teach competition because we do. We accustom people to the fact that they are mentally retarded, they are going to run into obstacles. By the time six months in the facility has passed, they are so inured that they have a sense of humor that is beautiful. If we walk into Friendship Facilities, and I have to use this for an example though there are many places throughout the country that are this way, we won't believe the attitude because we will see no mental retardation. We will see no physically handicapped. We will see the people that Dr. Stein talked about yesterday, "If we stare at a picture long enough, we do not see the chair, we see the person." It takes an enormous amount of time for somebody who has been socially maladjusted for twenty years and suddenly they expect Friendship Facilities to overcome the maladjustment in three months. We can't do it in three months. We do have failures, and we do cry about our failures. Sometimes we spend too much time on our failures rather than on our successes. The important thing is to give people activities so that they can fully relate and work together.

Equipment. This can be the biggest hangup in any program because suddenly people start thinking money. We wanted seven canoes. We have seven canoes and all the equipment that goes with them. They are aluminum 17-footers. We put on a puppet show and sold tickets. We raised enough to purchase the canoes because a dealer who sells Hondas and canoes offered us discounts and we gladly took it. We do get the equipment to promote our programs here whether we need minibikes or something else. We have horses on our property. The horses were given to us because the former owners got tired of taking care of them. Now we have the problem of getting tired of taking care of them. They are great and the young people love them. This is not necessary equipment and I don't mean to consider the horses as equipment.

We have to have something materialistic as well as something intangible to sell a program. If we are going to take people bowling and the bowling ramp costs $250 because it is made of chromium steel and it has a couple of emblems on the side, this is not what we need. What we need is a 25¢ construction piece of hoop bent so that it forms a ramp so a person who is cerebral palsied and in a chair has only to push the ball down after he lines it up. We do not have to go overboard in money for many of these things. I will tell you what we did for some of the things that we needed. We simply went to a carpenter and gave him an idea of what we wanted and the things were donated to us. Equipment doesn't have to cost money and there are many ways of getting it.

Building. We have what we call the Phoenix Building. If you are familiar with the legend of the Phoenix bird, you know that many thousands of years ago, the famous bird was consumed in fire. Every five hundred years it rises up again and is born anew. This is even our emblem for our Air Explorer Post. We have it instead of an eagle. It is an emblem and it is pretty close to the Eagle Scout. We call it the Phoenix because these are Explorer Scouts, not Boy Scouts. We do not put the mentally or physically handicapped in Boy Scout or Cub Scout uniforms. We move them up from cubbing or scouting to exploring. If they are mentally ill, if they are alcoholic, or if they are socially maladjusted and of high IQ, we put them on the advisory council and they become a committee to serve the people who cannot cope as much as they can.

The building must have physical accessibility if you are going to use it as a regular meeting place. The Phoenix building fell down while we were constructing it. A nuclear plant at Morris had to move a building and also a church twenty-three miles away. We were told it was impossible to do. We moved a solid building twenty-three miles away to Friendship Facilities. It cost us $10,000 for the entire upgrading of the building. The physical accessibility changes cost $10,000. That building is worth over $100,000 today and we put $10,000 into it. We must watch for these types of opportunities. The Phoenix Building got its name because while we, as a group of laymen construction workers, were putting it up, a huge windstorm came from the south and twisted the girders and knocked it down. We looked at it and tears were streaming down our faces. It was so disappointing that we had put so many hours into the metal work in order to make the Phoenix Building and that storm came and twisted the girders. After two weeks we had untwisted them, every girder, and put the building back together again. Within a month we had the building constructed and it is one of the most beautiful buildings to be found in the field of working with the handicapped that you will ever see.

The building has to be accessible. The building has to have, of course, bathroom facilities for men and women. They have to be identified and as all of us know, we identify them not by word but by symbols. We put the words below it, simply because the people using them have to learn to recognize words as well. Everyone doesn't have a Senor and Senorita on the doors, or rooster and a hen.

Making it Work With Your Resources

Transportation. Another thing we need to talk about is transportation. Transportation, when working with the handicapped, can be a big problem. We have a van without a lift. We have people in chairs. We have people who are ambulatory. They often come late. A time is set for the van to pick up certain people who, perhaps, are going to the disco. They are going to be picked up at 6:30. Three people may be on time and the rest of the people show up a little later. It is necessary to have them start on time. If we set the standards, we are not going to have this problem. But we should not start sympathizing with the participants. Let them learn to start earlier, have their dinner earlier. If we start by setting standards, we are not going to have the transportation problems except once in awhile and it is usually with new people who are referred to us.

Dues. We are setting dues for our club because this organization should be self sufficient. If people are going to come to the disco, they may be going to have a can of beer which they can't have downtown. Sometimes they can't even go into a tavern downtown simply because of the cosmetic situation. I am sure you are all familiar with what I am talking about. We don't charge for the beer.

Mainstreaming. We have talked about our organization. What do we have to do about the participants? On the back of your card you can read about social integration among the disabled and the able-bodied in leisure time activities and a ratio one to one. If we are going to mainstream a club, such as Sons of the Desert, and it is composed of all handicapped, we are not doing our job because we are not getting that person in who is going to relate to or who is going to help with the handicapped. The ratio of one-to-one is very important because we can become top heavy with the handicapped or top heavy with the able-bodied. We lose our perspective so that we try to get an approximate one-to-one relationship with so called able-bodied. I have seen films many times that say everyone is handicapped and I sometimes think we are in some respect or another. We try to keep a one to one relationship, but we have an open membership. The open membership means that anyone can join up to the limitations of your club membership. I heard yesterday somebody was telling me they have a YMCA membership of 24,000 people they have to deal with. It's just beyond my comprehension, but it must be fantastic. They must have one of the finest programs in the world to keep track of that many people and to have them stay as continuing members. The ratio one-to-one and our goal is mainstreaming. Mainstreaming is a beautiful word because we have to have some word that describes what we are doing. I like mainstreaming for the simple reason that it works. It is the best thing that we have going in this country today because if we have isolated groups, we are not Americans. We have one group, handicapped or non-handicapped, and it is working. That is mainstreaming, but I think that is the American way of life that has been envisioned by all of us.

Modifications on Activities. Modifications or adaptations are needed. It is necessary to be inventive. We invented several bowlograms some 15 years ago that are now the vogue. Many things have changed in the State of Illinois. One of them was the fact that we took people from a sheltered care home who came to work and received $20 a week or $40 a week. Some of our people make $150 a week as clients. If they make that much money it is immediately subtracted from the public aid check, from the supplemental income. It is not necessarily from the supplemental income, but especially from public aid. This meant people who stayed back in that sheltered care home would laugh at them and say, "You go to work for nothing." They say, "No, we are not going to work for nothing because we are paying our own way in life."

Making it Work With Your Resources

It doesn't make much sense to go to work to earn more and suddenly the people who are not working get the same amount of money. We sued the State of Illinois and said that we had to have a better system. Now those who work get to keep the first $20 and split the next. It is a much better system than when they came to a sheltered workshop. They earn money that those people who are not working do not earn. Those working also have the pride and satisfaction that they are not burdens on the taxpayer. They are paying their way. If they are able to produce, they should produce. If they are able to produce and at least garnish a little bit toward the end, this is what they are proud about.

Physical Accessibility. No matter what kind of program it is, if people with handicaps are involved, you have to know what is available and what type of modification may be needed. Only years of experience can give this knowledge and even then there could be problems. If the activity involves transportation, there must be capable drivers with adequate insurance to satisfy the Board of Directors of the agency involved. The board sets policies, the advisor sets administrative procedure. The board should not become involved in administration. If the advisor is not doing his job, he can be let go and a more qualified person hired. The Board sets policy which includes such things as setting the insurance requirements, setting qualifications of drivers including checking accident records. Also, they should set standards for drivers who handle handicapped individuals so they will be able to cope.

Goals. A goal is established, making Sons of the Desert as a bonafide club. Weekly meetings are set. This is an actual fact. The club has been in operation for many years. Weekly meetings are held for expediting travel, recreation and leisure time activities for, by, and with the able-bodied and the handicapped.

Fun and Adventure. In any program there will always be those with negative as well as positive attitudes. The thing to do is put fun into the program. As advisors we have to carry the enthusiasm, the motivation, the program no matter how we feel. We have to give them adventure and fun. An illustration of this is the case of an elderly woman, a senior citizen, who was dying because she had no reason to live. Her next door neighbor wanted to help her and decided to be a pen pal. She wrote a letter to the woman every day. The woman went to the mailbox every day and received a letter. It was exciting. The mailbox became a passion. She had a new lease on life and this generated into other new leases on life which gave her motivated life until the day she passed away. That mailbox and the woman neighbor next door made life worthwhile because it gave the atmosphere of suspense, adventure, fun simply by writing a letter. We have to be able to motivate people.

Charter. We have to obtain a charter which is not the easiest thing in the world because we are heading for a non-compartment charter unless the agency is the parent agency of the organization. We need membership cards and a steering committee. We have to have a membership drive, elect officers, develop the constitution and set quality, quarterly program. A quarterly program is a must;otherwise the program will fall apart. It is necessary to collect dues. Without money you are not going to succeed. The goals are listed on the back of your membership card. There should be a one-to-one relationship in both offices and members, however, do not try to lobby them whether the president chosen is able bodied or handicapped. If you have an approximately one-to-one relationship and they want to select their own leader, not who you as the adult advisor may choose, let them make their own selection.

Making it Work With Your Resources

Physical Resources. The meeting place, which has already been described, is the Phoenix Building. The owner of the Ottawa Bowling Lanes, which we use, is very helpful. He provided a ramp at the back door and one at the front door. YMCA swimming facilities are used. Scuba diving was provided at the YMCA for anybody who wanted to learn.

Finance. The chart here shows the club as solvent. Actually, there is money to spare. The programs have been very successful. The money is not coming from the taxpayers, it comes from the very people that participate in Sons of the Desert.

Relationships and Process. Responsibilities have been assigned and target dates have been set. The steering committee has been formed and steps taken to obtain a charter. Officers have been elected and a constitution approved. An advisor has been selected.

Evaluation. The Sons of the Desert has been organized to become an operating body.

Conclusions and Recommendations. No problems as to logistics and membership and strongly recommend the mainstream approach.

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MODEL SYSTEMS: MAINSTREAMING

by

Dennis Breitholtz
Social Rehabilitation Director, Palatine, Illinois

For those who don't really know what Little City is, we are a residential home for the mentally handicapped and emotionally disturbed. We have about 180 residents at Little City today. They range in age from 6 to 53 and in levels of retardation from profound to borderline. Borderline would be an individual who, for all social appearances, does not appear handicapped, but may have some academic deficiencies, or some learning disabilities, or had some learning disabilities when he was younger.

The model system that I have is basically a YMCA. About six years ago I started taking the children or the adults out in the community and realized that many of them didn't understand some of the basic concepts of even a simple thing such as how to use a vending machine. They didn't know how to do it and there was no reason for them not knowing how to do it so we taught them how to use a vending machine.

The choices that they had for their leisure time seemed to me to be totally inadequate. They ended up playing bingo, sitting around watching TV, or whatever. Basically, many of them were just withdrawing so I realized that they needed to have choices. Their potential was unknown to me because I had never, nor to my knowledge we had never, exposed them to a variety of things. Many of them, I thought, could learn how to and should be able to use restaurants and bowling alleys and all of that. I really did not want to go out into the community with a herd of handicapped children and rent a bowling alley because it also occurred to me that many of them, after having experienced those situations, could use it by themselves.

That was my ultimate goal and is Little City's ultimate goal; to raise each individual to his highest potential through exposure and programming and many other things. The activities were necessary and we wanted to teach them or expose them to a variety of activities. We were more concerned and still are concerned with the processes that go on in being involved in that activity. If we are going to take them to a movie theatre, that is fine. An individual can see a movie and he can also watch TV. What I wanted to do was expose him to buying a ticket, to confronting a ticket person, to stand in a long line and be able to deal with people pushing and shoving. Then, when they get into the theatre, they should be able to communicate with each other about where they are going to go sit so they don't get lost. (This has happened many times when I let the children off). Basically, we wanted them to go through the processes and the steps necessary so that they could use the theatre by themselves so I didn't have to go with them. I could just drop them off. This worked. We taught quite a few of them to use movie theatres by themselves and also the restaurants and whatever.

The problem then became very obvious to me that it was not a problem of mainstreaming the children into the community. Rather, it was a problem of getting the community to accept these mainstreaming individuals and to deal with them as people rather than as handicapped retards to either be placated to or be shoved away. As an example, we started using a restaurant near our facility and after a month, our people were using it on their own. I went over and asked the waitress how they were doing and she said that they were driving her crazy. They would come in, eight of them, sit down, and one would order a coke. She would run and get it and bring it back. Then one would order fries. She would run and get that and bring it back. She would just continually run back and forth like that. She would come with the bill then, hand it to them and they would say they wanted separate checks so she had to make separate checks. I asked her if she would tolerate or give that kind of service to normal people that came in and treated her that way and she said, "Absolutely not, but these were handicapped." I said, "Yes, they are handicapped."

I took them aside and told them that they were driving this woman nuts and I really didn't want to hear about it. I wanted them, when they came in to the restaurant, to sit down and ask each other if they were all ready to order. If they were not, they should ask the waitress to come back later. They never did tip her either, that was another thing she complained about. When they were ready to order, they were to order at one time and get their food and eat it. They should ask for separate checks, initially, if they wanted them. I showed them how to figure out what their part of the bill was and to figure out how to tip her. If she was not giving them good service, they should not tip her. They did that. I went back a month later and they were doing fine.

The problem is that people in the community treat the handicapped as if they were handicapped. Now all of the handicapped happen to be handicapped, but they are all also individuals who differ as broadly as we do in their capabilities, their potential, their personalities, their character. You can not categorize them and herd them and expect to do anything but keep them that way. The restaurant process worked and the movie theatre worked for a large number of our population. Then another problem came which was transportation and the use of transportation. I was tired of driving back and forth. It was as if I had 180 children and one wanted to go to the movie and one wanted to go this way and one wanted to go that way. I ended up driving all over the place. They had to learn how to use public transportation which we taught them.

The problems are more involved than this. I am just giving you a brief overview. There were classes also on how, in a restaurant for instance, to read a menu and to evaluate whether or not they could. If they could not, then we had to compensate. Just because they couldn't perform the way we do should not mean they could not go to a restaurant. They could ask a waitress what was on the menu and how much it cost. There are ways to teach them to compensate.

We expanded on the entire concept about two years ago and built a community social center which is a replica of a YMCA. It has an indoor swimming pool, exercise room with universal equipment, game rooms, whirlpool, etc. Again, the activities are good. We try to offer the same kinds of activities that they would find in a Park District or Y. Activities include aerobic dance and when they see Farrah Faucett, all the girls want to dance too. The boys and the men want to body build. They all want to swim. We offer the Red Cross swimming lessons with those levels as well as the YMCA swimming lessons with the polywog or whatever. This is so that if an individual does want to join a Y or a Park District, he knows the language.

Again, the processes are what we are concerned with. It is not necessarily going swimming, not necessarily weight lifting. I do not care what they do as long as they have developed the ability to make a choice with their time because they are human beings and they have the right to make that choice. What I think is right for them is irrelevant as long as they have been exposed to a variety of things. Then it is totally their choice. What I was concerned with was the process so every eight weeks I have a registration. I send out a mailing to all of the participants. They are required to mail it back to me and register by the mail. It is very simple. If they find out they can't do that, those that I think should be able to do that, I will have it worked on in classes and have special education deal with them and try to teach them the processes of filling out registration forms. If they are having a difficult time scheduling their time, we will do that for them.

Money is a basic reality if they are going to be mainstreamed. All of them have to deal with that. "Can I afford it?" We control the economy at Little City, which is good, so we make realistic prices. We have a membership to the Community Center which they have to pay for annually or we break it down into quarterly installments and they would have to pay them interest on that so they learn that process. Each class has a price tag too as we are working and achieving within a vocational setting. They can again use the monies in a very real sense to pay for social experiences. We then set up the same reality that all of us function under which is that the harder you work and the better you do at your job; the more money you get and the more you are going to be able to do. At any rate what we are concerned with is that each individual, after he goes through that process or when he is involved in that process, can then be encouraged to use outlets within the community so that he starts using these outlets, not as a handicapped person necessarily, but as an individual. He starts using the Y and getting involved in a normal program. He starts going to social outlets like restaurants, movie theatres and can just be a normal person doing that.

Thank you.

MODEL SYSTEMS: MAINSTREAMING

by

Patricia Condon
Chicago Parks District, Chicago, Illinois

The Chicago Park Department has actually been mainstreaming since 1965 although the program was not designated as such. The Park Department serves all of the community in the City of Chicago from the tax base paid by the City of Chicago. The program is not restricted to residents of Chicago, they can come from any place.

In 1963 the program staff heard about the program sponsored by the Kennedy Foundation. The Chicago staff was trained in regular recreation activities, sports activities and the like, but the Kennedy Foundation program was new. Through a cooperative effort with the foundation, instructors were sent to a summer camp in southern Illinois for staff working with mentally retarded incorporating them in recreation and sports programs. Helping with this also was the Easter Seal Foundation.

In 1965 the Chicago Park District began a program for the mentally retarded. There are now full-time programs in twelve parks. Many activities are offered; fitness, gymnastics, basketball, swimming, and many others. At this time the programs were segregated ones because most of the instructors were new at working with the mentally retarded. Although they were trained in the field of recreation and physical education, they had to learn to work with mentally retarded. Many of these people are now Park and Playground Supervisors. They now deal with many facets of the community dealing not only with normal children, but with children with numerous disabilities.

In 1968 sports competition became a part of the program, the Special Olympics, the first of which was a track and field meet for mentally retarded children at Soldiers Field. This was actually a competition where people were racing against each other for a medal or ribbon. Since this had not been done before, no one knew what the children could do. It was important to the children involved to have instant feedback. Winning or losing was not the most important thing - participation and finishing were. A medal or ribbon was given every child who crossed the finish line as a reward for effort. It was the start of the building of a self image for each participant. Today the program probably includes 1,000,000 athletes in the United States. Probably 15,000 come from Illinois, 10,000 of whom are from Cook County. We now try many different sports with these people.

To get back to mainstreaming, this is what was done in the program. We might still be in segregated programs in the classrooms. Many children are in special education classes in sheltered workshops. This includes older people who are in day care centers or independent care facilities where attendants bring groups to the activities.

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Except for Special Olympics, in most of the activities offered in Chicago, participants spill over into normal programming. The department does not ever want to get to the point where they were destroying the feedback level that they began to establish to raise the self image of the participant and build his confidence and self worth in the community, his family and his job.

The Chicago Park Department has an innovative program and feels it is doing a good job. What is needed is to improve, increase, and expand it. Any program must start slowly and push hard until there is a breakthrough. Since many people are now interested in mainstreaming, if everyone works together it will then be possible to get together and talk and see if other barriers to the success of this need to be broken down.

MODEL SYSTEMS: MAINSTREAMING

by

Vicki Conley
Access Living, Chicago, Illinois

First I want to tell you a little bit of the history of Access Living. About two years ago a proposal was written by the Rehab Institute to apply for Title VII monies. Title VII monies came from an amendment of the 1973 Rehab Act. 504 is part of that act which is our civil rights. Title VII was for the severely disabled. One of the things that was occurring was that in the past 20 years many innovative and expansive programs were occurring to give a great deal of vocational potential to the disabled. However, those people who were severely disabled, who weren't vocationally oriented, were being excluded from much of the services. Title VII is to help those people who aren't really vocationally oriented and this is what Access Living's focus is about. We are there to give peer support and help in advocacy situations to the severely disabled. We want to help develop the independent living skills as much as possible to those populations. In 1978 a proposal was written by the Rehab Institute of Chicago to apply for these funds. Our agency, along with nine other agencies in the country, were awarded this grant so that in 1979, in November, Access Living's doors were opened.

We have several services that we are providing to the severely disabled right now. We have the housing department. This department is to facilitate people in finding housing. Many disabled people that we work with are institutionalized. They are in nursing homes or they are stuck in second floor apartments with their families or friends and can't get out. They have been this way for years and years. We are trying to access apartments. We are also trying to work with Section VIII and CHA, you know, Chicago housing to access more apartments. This part of the job is very slow. At the moment there is an eight year waiting list for Section VIII certificates and if you do not know what that is, it is subsidized housing. Disabled people are often on a very strict income and, as you know, a grant for an accessible apartment is usually a minimum of $300. Most of our clients get about $200 a month to live on through SSI or SDI so trying to access apartments is really difficult.

We are also starting to work with architects and developers to make their units more accessible, work with landlords, realty companies to keep in mind that disabled people also need apartments. We do a great deal of housing counseling in this area. The success rate is not very high at this time because of the difficulties in trying to find this kind of housing. Those that are accessible are usually the high rise and, of course, they are very expensive. Those that are not as expensive are usually in ghettos and are not safe so the disabled really have a problem.

We also have another program called financial benefits and independent living skills. We have a coordinator for this program and her job is to give as much assistance to the resources available to disabled people, financial resources, as possible. She also helps these people develop an independent living skills program within Access Living. Many of our people are multiply handicapped and consequently need many different services from us. Because most of our clients have been disabled since birth or early childhood, their learning process was not the same as able bodied children so they didn't learn about decision making skills. They didn't learn about problem solving skills. This is what we are trying also to teach them.

Another program we have is the personal care assistant program. This is a program in which we do a great deal of outreach through newspapers and word of mouth to find people who are willing to be personal care assistants and/or homemakers for disabled people. Many disabled people, including myself, could not be independent unless we had a PCA, personal care assistant. This is a program in which we do our outreach and then we do a five-week training program through the city colleges. After these people have gone through the training, we then refer them on to our clients who need PCA's. The client is then required to check out the references. We give them three references. They are to contact the person, the potential PCA, and check out their references and then they also do the hiring and the firing. All we do is refer.

Another program that we have is a new program that is funded through the Center for Independent Living in Berkeley, California, which is the forerunner of all Independent Living Centers. This program is called 504 and we have hired somebody who takes care of issues of discrimination. She has been successful so far in working with a case where there were some hearing impaired workers at the post office who were being discriminated against. Through her negotiations many of their problems were resolved without going to court. The success rate in court is not too high so we try our very best not to get that far and negotiations are usually pretty successful.

The last program that we have and which is what I coordinate, is the educational component. This is the independent living skills. We teach all different types of independent living. There are three workshops that I offer that teach concrete skills and these are housing options, financial management, and personal care assistant management. These three are for people who are ready to act, are ready to put all of these resources into action. The housing option teaches people how to find accessible housing, what resources there are, what kind of issues you personally need to think about in terms of your own living environment. What issues are you going to need to think about to be independent? Are you going to be able to do your laundry? Can you do your cooking? Can you clean? Can you get up by yourself? How are you going to do your grocery shopping? How are you going to do your laundry? We discuss all of these issues and amazingly, many people have not had to think about these kinds of skills. We are getting them to start problem solving. Once they have gone through the workshops they have found that what they thought was a dream and was not really reality oriented for them, is in fact very realistic.

The financial management workshop is just that. We teach them how to set up a budget, what kinds of things are going to go into a budget. One of the things that we emphasize is do you leave enough money for fun. This is something that everybody, not just disabled people, tend to put on the bottom of their list. We really advocate entertainment and fun is as important a part of independent living as paying all of your bills. Without it, independent living isn't all that great if you can't go out and have a beer with your friends or have a party or whatever.

The personal care assistant management workshop is also managing your personal care assistant. Our clients don't know anything about how to interview. We have to stress to them that they have a complete stranger coming into their homes to provide personal care. They have to get you up in the morning, get you dressed, feed you, do whatever you need done. You had better make sure that you're getting somebody who is trustworthy. I have heard terrible horror stories, not through our program, but before this program started, where people will come in, get the disabled person in bed and then rip them off completely. There is not anything they could do about it because they couldn't get up or get to the telephone. We tell them these horror stories so that they will be more conscientious about the kinds of people that they will hire. If they go through Access Living, we have done an interview and a screening and they have gone through the five-week training program. In that training program we emphasize to the potential PCA's that the disabled person is their employer and they are to do what they tell you to do. "You are not a nurse. You are not a helper. You are to do what they tell you to do." On the reverse side, we tell our disabled clients, "You are the boss. You better know what you need done and you better set up a schedule because otherwise the people that you get from us are going to sit around and do nothing."

This is one of the complaints we were getting so we are having to really emphasize to the potential PCA's that while there is a segment of this population that can really handle that, that you can be directive and act like a boss. There is also a large section of this population who have never developed these kinds of skills so the PCA may need to make some suggestions to them. Under no circumstance is a PCA to tell them what should be done. A PCA might want to suggest that it would be very helpful to have the schedule so she/he would know what the job duties are. We tell our disabled clients that it helps your PCA's happiness and ability to stay longer if you are more organized, if you could tell them exactly what needs to be done and how to do it. We describe how to do interviews, how to set up schedules. We also talk about the communication and how important that is that you treat these people, not as robots, but as human beings who are offering you a service. While you are paying for it, you must be courteous to them and keep their happiness in mind.

We have four self-enhancement workshops and these are for the people who are not ready yet to move out on their own, to hire people, to set up a budget. They are still in the nursing homes or they are still in their parents' house. Their self confidence needs to be built up so that is what these workshops are about. We have communication workshops, assertiveness training. This is to teach them about making assertive statements and how this can help in self-advocacy skills because eventually a person will need to be able to speak up for himself and deal with issues in everyday living. We have a human potential workshop and this workshop goes into patting a person on the back, telling him that he is a good person, recognizing what his strengths are and building on those. We do some values clarification and we also do some problem solving and goal setting. The RAP Group, which is another one that we offer, is unstructured. It is a chance for disabled people just to get together and talk about whatever issues are bothering them.

The last group that we offer is self image and sexuality and amazingly enough, this is our most attended workshop. It is a four-week workshop although it is going to be expanded into six weeks now. This is the opportunity for disabled people to rap with each other about these very intimate topics. It is their chance to get some questions answered that maybe the nurses and doctors couldn't answer. It's their chance to really get down to the nitty gritty of sex and we make it okay to talk about sex. We encourage people to ask questions. We show films. We also have a panel of disabled people and spouses of disabled people who are not disabled come in and answer questions and share their experiences. This has proven to be one of the most helpful workshops because sexuality is a topic that many people can't deal with very effectively.

All these workshops are about and are planned to develop the independent living skills. All of the workshops are facilitated by disabled people. There is a great deal of peer counseling that goes on, a lot of role modeling. At Access Living the core staff is, all of us, disabled so we all act as role models and do much peer counseling.

We have another program that is called the staff associate program and this is a training program for disabled people who have never had the opportunity to work, who need to know what it is like to work. They learn about the kinds of behavior that is expected, the kinds of skills they could develop. Many of our staff associates provide support to us in our daily activities. They are receptionists. They help us develop all of the resources that come in. I have a staff associate who helps me put my workshops together and it is a very good program that is open to disabled people. I interview them. I take care of this program so I have an interview with them and I set it up like it would be if it were a real job interview. Most of the people have no experience or very little experience. That is okay because we will supervise them on the task that they will be assigned. It is part time work, not more than 20 hours a week, and they are paid minimum wage so they do earn a little money. Many of them don't want to earn very much because it will affect their SSI or SSDI. This is just a very beneficial program where they can learn some good skills.

QUESTIONS AND ANSWERS:

Question: Who pays for the PCA. How are they salaried.

Vicki: Through the Department of Rehab Services there is a new program called Home Services and if the disabled person is eligible, Rehab Services will pay for it. It is such a new program that there are many new things going on that I am not up on. As I understand it, the eligibility requirements are that you are not vocationally oriented, but that you do have a need for an attendant and they will provide as much care as is needed. They will provide twenty-four hour care payment for that care. The idea is that they will do as much as they can to keep somebody out of a nursing home, but if it becomes cost effective for that person to be in a nursing home, then that is the alternative. There is the Department of Aging and then there are all kinds of Home Health Care agencies. That usually costs $6.00 to $7.00 an hour. When I first moved here I needed an attendant and didn't have one. I was having to pay $7.00 to get a bath.

Question: Do people from Little City ever leave Little City and live in the community? Is that encouraged?

Dennis: It is encouraged. It depends upon the individual. We had one fellow that just left and got an apartment and a shop where he is supporting himself. Quite a few leave, but again, they have to be able to deal with all the skills that she was talking about - money management and all the rest. They have to learn to bank, to budget and all of that. Many leave, but there are some that are on the grounds. One policy we have is that when they get to a point where they are self-sufficient, we want to get them out of there. We have to cut the umbilical cord. Sometimes we have to say, "We are going to pack your bag and put you out. This is it. It's an easy ride here, but you have got to go out and support yourself."

William McCahill: That is one of the values of meetings like this. When you find out about services like those you have just heard about, if your agencies need some of those services, at least you know where to go.

Question: Do you have any retarded people in the Chicago Park District?

Patricia: We have one young man currently on summer work, in fact, we have more than one. We have, I would say, four to five in landscape and things.

Question: Is that CETA money or is it Park Service money?

Patricia: No, that is Park Program budget money.

MODEL SYSTEMS: MAINSTREAMING

by

Stewart Mace
National Easter Seal Society, Chicago, Illinois

Before I begin, I think maybe I should explain a little about Easter Seals and my role in Easter Seals. I represent the National Society which does not provide any direct services. We have affiliates in every state in the country and local affiliates in most communities and it is at this level that our services are provided. Most basically we provide services to individuals who we over the years have called physically disabled. That has changed dramatically in the last five to ten years and the persons that we serve now are generally the very multiply handicapped individuals. In most cases they are individuals who are both physically disabled and have some degree of mental retardation.

I would like to share with you three models of really reverse mainstreaming that some of our local societies are doing now. I use the term reverse mainstreaming, I guess, for lack of a better term. What we are trying to do is train the "normal" individual into some of the programs that we have had over the years and which have been basically segregated. One is a camping program in the state of New Jersey, Camp Maryhart, which serves approximately 70 individuals at a time. The children and adults come for two-week sessions. It is important to point out that we are serving adults also. Over 50% of the campers are over age 21. Two or three years ago at Camp Maryhart it was decided that the process of integrating our campers into other camps such as YMCA or Girl Scouts, etc., could go only so far. There would always be some campers who had a disability to such a degree that they would need a special environment. We decided to attempt to bring the "nondisabled person" in the camp and so, running concurrently with the resident camping program of the 70 disabled campers, is the day camping program.

There are 35 campers, children from the community around the camp who attend for two-week sessions. They come about 8:00 in the morning and stay through about 5:00 in the evening. They participate with the resident campers on an equal basis, go to all the activities, help plan some of the activities. They eat meals with the campers, and even on a couple occasions during the two-week session, they will stay overnight at the resident camp and go on a campout with an age group that's comparable to their own age. Through this process we feel we are helping both groups. The children in the community who come as day campers are becoming aware of some of the needs that the very disabled campers have, as resident campers and vice versa. Many of the resident campers come from communities where, in their school system, they are basically in segregated classes and so they are being introduced to having leisure activities with the normal children.

A second program that we have happens to be in Connecticut with Hemlock's Outdoor Education Center and is what we call a "Buddy Program." This occurs during the spring and the fall and is basically different from the resident camping program in that the campers are invited for weekends and they are encouraged to bring a buddy who would be nondisabled; a friend from school, someone in the neighborhood. When they come to the camp they participate as

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friends. The nondisabled child is not an attendant for the disabled child, but they just go through all the activities together. A new twist that we are adding this year is that we have found that some of the campers could not attend these buddy weekends because they just did not have a nondisabled friend at home who would come along or could come along. We've begun what we call a "Buddy Bank" and through other agencies, such as the YMCAs and Boy Scouts in the communities around Connecticut, we have developed lists of nondisabled boys and girls of different age groups. When a camper would like to attend at one of these buddy weekends, but does not have a friend, we can match them up. It is like the old computer dating game, I guess. This is the first season that we have tried this and we have not been able to evaluate it yet. We hopefully feel that it will have some carry-over value the rest of the year when these children can go back into the community and having met a new friend will continue that friendship.

One other model I would like to share with you is a recreation model in Peoria. Our Easter Seal Society there a few years ago determined that there seemed to be a real lack of recreational opportunities for disabled people in the greater Peoria area. They hired one of the professors from the University of Illinois, Dr. Carol Peterson, to do a needs assessment for the Peoria area with the help of her graduate assistants. They determined that, in the six-county area, there were quite a variety of services available for different groups of individuals although there were quite a few gaps in the services and in some cases duplication of services. Their feeling was that someone in that area needed to take the catalyst role and develop a system where those different programs could enhance each other rather than combatting each other all the time.

The Easter Seal Society in Peoria, beginning last month, started a new program where they are going to first of all take the individuals, the handicapped individuals who are not involved in any recreation program now, and provide the recreation service that appeals to them at that point. They will then begin a process of major education trying to expand the horizons of these individuals and get them interested in other types of recreational services. The next process would be then to educate these individuals on what is available in this metropolitan area. They will also be working with the different agencies in preparing them to accept some of the disabled people into their programs, both from the point of the program and also from the facilities. The Easter Seal Society will be educating the professsionals and also the students in that area. The idea is that, in a few years, the metropolitan area of Peoria will have a system of recreation services where the individual can choose the type of leisure activity that interests him and he will have the knowledge to find that service and then those services will be available. Briefly, these are three types of systems that we are using and I would be very happy to entertain any questions or comments.

MODEL SYSTEMS: MAINSTREAMING

by

John Sullivan
Superintendent, Friendship Facilities, Ottawa, Illinois

I would like to mention "Partners in Progress". Easter Seals has a program in Ottawa, Illinois for the handicapped. It is a very important program and the Easter Seal Society has given much expertise and sophistication to this program which is Partners in Progress. The same can be said for many agencies that overlap.

I want to introduce you to the Post Advisor of Post 115, the Explorer Post part of the Scout Program, Bill McCahill. Bill probably has one of the most enviable jobs in the world. This year he will be taking a group to Acapulco. We have sent groups to England and Scotland. Last year he took a group to Disney World, Seaworld and Circus World in Orlando. He flies with them. He takes them to the YMCAs in their various programs. The job is strictly scouting in a facility and he has about 90 people he works with. Scouting has no programs, there are no posts, there are no troops. Boy Scouts do not provide or attempt to operate scout troops with active posts. In other words scouting will take a program if you wish to avail yourself of it. You provide the leadership, you provide the committee, you provide the program. Now the Explorer Program which we have is the Explorer Program for people over the age of 14. Over the age of 14 they can go into a specialized organization. One we have in Ottawa which is very,very successful in the mainstream post is the law enforcement force. They have many people who follow this type of program. It works. It is a good program, but again, it depends on the leadership.

I want to talk about why we are watchdogs with the handicapped, why we have financial advisory committees as a specialty for the handicapped. Well, if you recall, the Boy Scouts had two lawsuits in the past two years. Mr. McCahill and I are very heavily involved. It cost quite a bit of money, there was a great deal of litigation. A boy, in order to make Eagle Scouts, had crawled on his hands and knees for fourteen miles to qualify. He was denied Eagle Scouts because of semantics and a few other reasons. The lawsuit was filed against Boy Scouts of America. Five boys were cerebral palsied and completely bedridden. The scoutmaster applied for Eagles for these five lads. They were completely, as I said, bedridden. The scoutmaster was not quite truthful in his statement. They were denied the rank of Eagle.

Consequently, there was a national explosion from the newspapers. The media played this up. They were not interested in why this happened, but they were interested only that it happened. This is unfortunate sometimes on the part of reporters. They were turned down simply because of the laws which stated and stated explicitly what had to be done. We had to change the laws and under the guidance of Bill McCahill, we changed the laws. We are a nation of lawful people, but we must make a law that pertains to all. If the law specifically states that an individual must carry a pack, the words say, "You must carry a pack." Suddenly a lad who is in a wheelchair who wants to get

Model Systems: Mainstreaming

The Eagle Scout which is Boy Scouting's highest award, cannot get it because he cannot carry a pack. It is then necessary to change the wording to "tote" or "Have the tote with you." Consequently, you can meet the requirements.

We are going to Dallas next week because someone who is a great promoter of aquatics is now instituting swimming at its highest degree back in the first class award. We become watchdogs. I am on the Merit Badge of Winners Committee. Every merit badge has to be checked out. For the handicapped, this is mainstreaming. Words have to be changed for cooking, hiking, camping, etc. Right now they want to create a rule that will knock Eagle Scouts out for the handicapped. The opportunity for every boy to make Eagle Scout must be there and we are more or less watchdogs to see that the handicapped have as much right to earn the award as anyone else. We go to Dallas to meet about this. I have been assigned to the National Advancement Committee. When they consider this rule, my job is to see that it is worded so that becoming an Eagle Scout is available to the handicapped.

Last year we promoted one of the finest operations that we consider in scouting. We promoted the merit badge for the non-handicapped scout and the requirement for one thing is to serve at Easter Seals, serve at a place like Little City or Access Living. There are several requirements that have been designed over the past seven years and modified until this merit badge is a reality. Not too long ago the merit badge was put on a loom and we received the ones that were made that day.

The second thing I want to talk about is the "Awareness Trail" we have at Post 115. There is a trail of fifteen stations where the non-handicapped go through. I explained it to some people yesterday. You go up a ramp in a wheelchair and make a right-hand turn. You pull a door toward you, go through the door, make another right-hand turn and you get on the ramp. Thus, you have some idea of some of the physical accessibility that is needed. This is on loan to every organization in the State of Illinois. They even come up from down in the southern part of Illinois in Carbondale to borrow the apparatus. If anyone in the state of Illinois wants to borrow it, it costs about $500 to manufacture with the entire stations and the Xerox and everything that goes along with it. You are welcome to just write us a letter and use the "Awareness Trail."

HEALTH, FITNESS, AGE

by

Neil Sol
George Williams College, Downers Grove, Illinois

I don't know about you, but I refuse to grow old. I'm just not going to let it happen to me. A statement that those of you who work with people who are older Americans might use when you deal with this population is to grow young gracefully with exercise rather than old. You'll find that it is a fallacy, as Rich had indicated, that you degenerate with age. Exercise studies with aged people have shown that regular activity has the ability to retard those physiological degeneration mechanisms that occur due only to aging process. It has been shown that senior citizens who exercise on a regular basis will gain benefits from training that are similar to those individuals who are younger. If you are 25 years old and you jog every day, the benefits that you derive from jogging are not different from those derived from somebody 65 or 75 years of age who jogs.

Proper physical conditioning (cardiovascular in nature) which includes such things as walking, cycling, swimming, cross-country skiing or jogging are not barred from people who are older. Seniors can also perform calesthenics of various types for flexibility, muscular strength and muscular endurance. They can take part in competitive sports and activities such as tennis, golf, badminton, road racing, swimming, racquetball, etc. Physiological research suggests that regular moderate exercise will result in a lowering of the heart rate in the performance of a given amount of exercise. That means it would be easier to perform a given amount of work.

Exercising on a regular basis will also result in quicker recovery from a given bout of work. Therefore, if you walk up two flights of steps, you won't huff and puff for an extended time; it may just be for a few seconds. There is also a decrease in the oxygen utilization for a given amount of work from regular exercise. Typically, if you do not intervene with the aging process, a given amount of work will require more oxygen suggesting inefficient performance. Training will decrease your need to utilize oxygen. It will decrease the energy that you need to expend to do a given task. Individual performance efficiency will increase. We also see that regular activity will decrease blood pressure retarding the typical elevation that accompanies aging. When blood pressure increases, the heart meets a greater resistance causing the heart to work harder. If you train, the pumping ability of the heart has a better capability of meeting that resistance. In addition, increased peripheral blood vessel that results from training reduces resistance decreasing the need for high blood pressure. Cardiac output is a physiological term for the amount of blood that can be pumped from the heart in one minute. The more blood that can be pumped out of the heart per minute, the greater is the ability to perform work, as the muscles are provided with necessary nutrients. Regular exercise increases the pumping ability of the heart thereby increasing the cardiac output. Aging alone will cause cardiac output to decrease, however, exercise in older Americans will reverse or halt this trend.

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Health, Fitness, Age

It has been suggested previously that aging causes a decrease in muscle mass, increasing the relative contribution of fat to body weight. Regular exercise increases muscle mass. This occurs because exercise creates the need for muscles to hypertrophy, they will regardless of age. Exercise also decreases the percentage of body weight that is fat. Senior citizens are not doomed to sagging, pear-shaped, unattractive body conformations. You can actually develop conformation that can be attractive. I have been affiliated with people who do exercise on a regular basis who look really better than most of the people at 30 years of age. One of the things that exercise does is it increases the functional tissue. The increased caloric expenditure of exercise decreases body weight by requiring the metabolism of fat reserves. Height-weight charts after the age of 25 allow a gradual increase in body weight of about a pound to two pounds of body weight per year. This is because metabolism decreases and the extra calories are stored as fat. Exercise tends to increase caloric expenditure and all the excess food that would have been stored is utilized by performing the exercise activity. So, basically, there is an increase in functional tissue and a decrease in per cent body fat and body weight.

Flexibility is one area where there has not been dramatic change with senior citizens. However, they feel that with appropriate training there can be slight improvements in flexibility. I think it is unrealistic to believe that senior citizens will return to the flexibility that they enjoyed as children, or at the age of twenty, however, they can expect significant increases in range of motion and mobility. As far as strength improvements are concerned, with appropriate training (Progressive resistance) there will be an increase in muscular strength. You actually can get stronger as you get older.

Muscular endurance is the ability to do repetitive tasks, hit a forehand in tennis, do many sit-ups, push-ups, etc. Muscular endurance also has been shown to increase with training and so has power been shown to increase in training. It's funny that in the Senior Olympics values for 100 yard dash at 70 years of age as opposed to 65 years of age, the 70-year-olders can run faster than the 65-year-olders. It could be a function of training. It could be a function of the people who are dealing with it, but it is shown that with age, with appropriate training, you can increase your speed and power.

It is not wrong for senior citizens to be concerned about physical fitness. As a matter of fact, the converse is true. It is probably the way it should be. You should be concerned about physical fitness and it can be accomplished with appropriate regular exercise. I need, however, to caution people who do work with senior citizens or work with any adult populations, that most exercise programs that are instituted should be done so with consideration of the following concerns:

1. Exercise should not be administered to an individual unless you obtain his/her personal physician's approval.
2. Exercise should be administered with reference to any disability that the individual may possess, and finally,
3. All exercise for all individuals should be on a progressive basis.

HEALTH, FITNESS, AGE

by

James A. Schommer
Executive Director, YMCA of Metropolitan Madison, Wisconsin

I thought I would just give you a little background of how Everett Smith and I got together and how we started working in the area of senior citizens. It was back in 1974, I had come over to the East YMCA at Madison. Because of financial problems, we had just had a physical director leave and I had to interview for a replacement. One of the resumes that came across my desk was from Yankton, South Dakota, the person was working at a geriatric home that had just opened up. It was a brand new geriatric home and looking at his YMCA experience and work capacity at a geriatric home, I was interested in interviewing him. I brought him into Madison from Yankton. He made the statement during the interview that what he had discovered was that they could take patients who were bedridden, who were just eating, sleeping and taking tranquilizers; put them on a wood board, turn them into the swimming pool, and that placing them in the pool and having them float on the wood board added something to their life. They found that the people were sleeping and eating better and, as a matter of fact, they had something to look forward to and that they would have fewer sedatives as a result of what they were doing. They said that they kept this process up and pretty soon, because of the buoyancy of the water, they were having their patients walk around in the water. Then he said that, in order to improve their range of motion, they were taking nerf balls and would throw the nerf ball at the person and hit him in the chest with the nerf ball. He would become angry and would throw it back at them. But, as a result, they were increasing their range of motion which meant there was some success.

As I heard these statements I thought, why was it necessary to wait until people are in a nursing home, possibly on their death bed, before anyone decides that it is time to do something to improve their lives? Why not take this program and put it into our YMCA and let people know that health is important to them? Needless to say, I hired the person because I, in my mind, wanted to develop such a program. I knew that there would be ramifications in terms of insurance but I thought I should at least make an attempt to start an exercise program for senior citizens who were mobile and currently living in our community. I didn't know what kind of response we would get. I took the new physical director over to the Manona/East Madison Coalition on Aging which was primarily an office with staff that were working with senior citizens. I asked if our East Y could be placed on their agenda. They first said that they didn't really know if they could put the YMCA on their agenda because it was fitted with fourteen items already. However, after learning that the President of Dane County Commission on Aging had been supportive in making the request, we were placed on the agenda. They made us Item 3 on the agenda. At the meeting when we gave our presentation on the concept of exercising to maintain mobility and to improve their health, the entire senior citizen cabinet became intrigued. It was interesting that we were supposed to talk for less than five minutes which we agreed to do. However, it took an hour

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and a half and it was not because we didn't try to sit down and not talk, but the people just kept standing up and asking questions because they were that interested in the whole concept of maintaining their health.

As a result, we said that we would like their support and we would like to be able to approach the senior citizens promotional network and ask people to come to an open house. We ended up having forty-three people coming to the open house to learn about our senior exercise program.

In the meantime, I had heard that there was a person who was traveling throughout the United States and Canada working on senior exercise programs. This happened to be Dr. Everett Smith. I called him up because when I found out that we were going to have such a success with a senior exercise program, I thought I had better seek more counsel and advice. He was from the University of Wisconsin and I called him to see if I could get an interview with him to see if we were handling our program properly. When I called him he said he had worked at the East YMCA as a volunteer flag football coach for about the last year and a half and if I wanted to talk to him, rather than coming over to the University, he would stop in at my office. At our first meeting, he agreed to be the consultant for our senior exercise program.

We have had, I think, excellent success. We have put on two workshops for the YMCA's in the Mid-America region. Mr. Len Covello helped with both of the workshops. We have been funded through the Dane County Commission on Aging in the past. The East YMCA Senior Exercise Program has been remaining as a model program for the Mid-America region. I will say that there are a number of senior exercise programs, but in Wisconsin I think that we lit a fire and it was because there was a need and a real opportunity.

The thing that Everett Smith brought home to me when we were doing the senior exercise program was the fact that if senior citizens will exercise, they can increase their mobility from five to seven years which means more and better independent living. Women over the age of 55 have a calcium loss twice as great as men. That is why you often hear of older women falling and breaking their hip or their elbow. It's because of the loss of calcium. Through exercise, you can not only (this is Everett Smith's study) maintain calcium, but you can improve the calcium in your bones. We thought that was a very important aspect.

I just thought you would like to hear about this model. I feel it shows that if you want to do something, you can do it. I also think this effort was of value. Thank you.

OLDER ADULTS

by

Richard Escutia
Systems Developer, Metropolitan Board YMCA, Chicago, Illinois

I am going to go on where Jim left off in relation to fitness activity and the aging process as it relates to the older American. We are categorizing. I have heard the same thing said about the handicapped individual, that we have a tendency to categorize people. For years we have had seniors in our YMCA programs. We have never recognized them because they have been mainstreamed by their own choice and their own attitude. They have become part of our daily activities, we don't recognize them. If you ask any child how he pictures a senior, he will imitate this kind of a staggering, shuffling type gait and describe them as old and dirty. You would be surprised at the kind of responses you get from children on what they feel a senior citizen is, but they don't see those who have mainstreamed themselves. So now we are trying to provide programs just for the senior. In some cases we are losing something at the same time. Let me go into the physical fitness aspect of it. This is probably the most important thing and is a means to an end as far as fitness goes and it doesn't apply to just the seniors. It applies to everybody.

What is physical fitness. Well, if I asked a weight lifter that, it would mean being the strongest person on the block. If I asked someone who was really into yoga, it might mean being flexible and tranquil and things like that. If I asked John here, it might mean being able to run ten miles at a time, but at the same time, the jogger might not be able to bend over and touch his toes. The individual who is very high on yoga may not be able to run a mile without getting exhausted. He may not be able to catch the bus if he is late.

Physical fitness is a total program that actually covers four main areas like four engines of an airplane. It covers body composition, muscular strength and endurance, flexibility, and cardiovascular strength and endurance. If any one of these engines is not properly working, then the plane will still fly, but not as well as if it had all four engines flying right. We need all four of those areas. We have been under a misconception in terms of aging process. I know Dr. Smith is working this area. People refer to what they call a "Euro-American curve." Now I will try to describe it for you. Picture the horizon or even the edge of the window and with a mountain out there. The mountain, of course, rises to a peak and comes down on the other side. This is how we picture the aging process of most individuals. We say that we start off at a certain level and we improve up until our thirties and after that it is all downhill. You may as well sit in your chair and call it quits. That is a fallacy. For one, we are assuming that everybody is operating at his optimal as he reaches that peak at 30, 35, 25, or whatever the case may be, and then he is not going to improve any more. We have proven that wrong in the last ten years just in the jogging programs. We have people who have never run before getting into programs. They are running better now at 50 than they ever did when they were 25 and 30. What is the reason for this? Everybody has a certain potential, nobody has really tapped this potential. In some cases we have avoided the activity altogether. You may have a senior in a program who has been an accountant all his life and has never done any kind of activity. Finally you convince him to do some walking and that feels pretty good. After awhile he is starting to jog around the gym and in a short time he is doing a few miles around the gym. The thing is that he has a potential, regardless of the aging process, to improve. The only man who I can say actually reached that absolute potential was Bruce Jenner. He worked night and day, as much as eight hours a day to train every muscle in his body to obtain a peak performance for the Olympics. He did just that and won. There he was at the age of thirty. After spending eight hours a day in training, there was no more he could do to show additional improvement. Those of you who have been at a desk most of your lives and start an activity program, whether you are 40 or 50 or 60, you are going to see some improvement. You are not going to be a champion athlete. You are not going to be, maybe, what you could have been if you had worked that hard when you were 20, but you are going to show improvement and it is going to change your lives. Neil Sol is going to relate to that later, but let us talk now about some of those changes that do take place with aging.

What happens usually starts about middle age. It is the complicated organs that start changing first. The breathing system changes on us. When we breathe heavily, as when we have to run to catch the bus, there are a maximum of 32 different sets of muscles that have to come into play to get a forced inspiration and a forced expiration. With lack of use over the years, these start to deteriorate. We see muscle fiber changing. There is not that ability to take in and provide as powerful a breath as there once was. We see an increase in vulnerability to disease, particularly heart disease, stroke, and cancer. We see a lower threshold to stress. This is the aging process. I need to emphasize this later again that some of these things are not the way things have to be. Some things we can not change. They are going to happen, but they don't have to happen as fast as they seem to be happening. We see changes in the skin. We have three layers of skin. The epidermis which is the outer layer becomes dry. Some of you may notice already that your skin gets so much more dry now than it did before. It bruises much more easily. The dermis is another layer underneath it and that starts to lose its elasticity. In fact some of you can grab the skin on the back of your hand and it will pop right back into place. Those of you that may have been around for awhile, it just doesn't pop back as quick any more. It takes a bit more time. We lose some of that elasticity that we once had. And then there is a deeper layer of fat, we call the subcutaneous layer. This is the padding around the ends of the bones and the sharp points that begins to disappear with age. The aged in the hospital have to turn over every 90 minutes or be moved because this layer of padding is not there any more. When bone presses against just thin layers of skin, it cuts off the circulation and those areas die if they aren't given the blood they need every so often. Bed sores are the result. So we find that that padding is very important. We think of the "Grandmother's arm" as the baggy skin on the back of the arm. This is the loss of some of these fatty subcutaneous cells that are in the back of the muscles and around the padding of the joints. In the aging process the fingernails and toenails get thicker, become more brittle. Part of it is a lessening of the circulation around those areas. We can work on that a little bit by providing warmth. Warm water helps to improve some of that circulation in the hands and keeps them a little more supple. Muscles are probably the one thing we notice the most. We lose muscle fibers. We are born with just so many muscle fibers to help us move our arms and legs and everything, and those fibers must last for a very long time. They can not be replaced when they are damaged or changed due to the aging process. They can not be replaced, but the job is picked up by other muscles and muscle fibers around them so that we can continue working. There are studies done on mechanics, which show that there is no change in work performance up until retirement. Even though there are changes in the individual muscle fibers, we find that when some muscle fibers die, others can pick up the workload for them, but there is no increase in the number of muscle fibers themselves.

When I did my research on the aging process five years ago, a number of the studies that I have included in my bibliography way back then were the same ones and the same people that Everett Smith has been working with. Richard Mazess is an example of people very well known in the area of the aging process and the elderly. But in many studies, we find, the only muscles that can be studied with any confidence are the eye muscles. These are the ones that rotate the eyes and probably are the most protected from any outside injury to them or diseases. If you try to study the long term effects of aging on any one particular arm muscle or leg muscle, you find there is a great deal of outside influences that makes it very difficult for research.

Bones - this one we probably recognize in our families. I know most people in their families at one time or other has had an aunt, grandmother, uncle, grandfather, who has had a very slight fall, maybe just an off-balance step which resulted in a broken bone. Well, with the aging process we find demineralization has taken place. The calcium content starts to leave the bones. Where does it go? Sometimes it leaves the body all together, in other cases it goes to the cartilage. The soft cartilage in our nose and our ears and between the joints becomes brittle, becomes hard, where it was once soft and pliable. It picks up the calcium that was once in the bones and settles in these areas. We start losing our flexibility and agility. We start seeing the curved spines and the other anomalies that I have referred to in our stereotype of the aging process.

Vision - there are changes in vision. Again this points up many things in planning our programs. We find that the depth perception isn't as good. Our color perception isn't as good, especially around blues, greens and violets. We have to take those things into consideration. Our nursing homes should have bright colors, especially around stairwells.

Hearing - there becomes an inability to hear high frequencies and here we run into a problem. Grandma says I can't hear you, speak up. We then use a high voice to talk to them instead of getting a low voice so that they can hear the deeper tones. The richer tones are those which they can hear, but not the higher pitched tones. It's not how loud you are, but the kind of tones that you use that will make a difference.

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Older Adults

Appetite - well, how many of you have already said that the food just does not taste like it used to? I know my mother says that all the time even though we still eat it. Part of the problem is that there is a reduction in taste buds. I see so many of our elderly who are shut in at home and who do not go out of their houses at all, barely ever eat. They just do not like the taste of food any more, but they don't realize that because of the loss of the taste buds, you can't pick up certain flavors. It just does not taste like it used to because the ability to pick up those flavors is not there any more. This is another reason why, in our nutrition sites, we concentrate on not only providing quality food, but having good looking food. By making it appetizing to the eye, people want to eat it. It is not because they can taste the food, but because it looks good that they eat it anyway.

Cardiovascular - this, of course, is very important. The ability of the heart to pump is related to muscle again. The heart muscle slows down, its contractural ability isn't as strong as it once was. The arterial flow may be reduced by as much as 35%. When you think in terms of the arteries, the arteries are very elastic. When the heart beats, the blood goes out and the arteries expand a little bit and then they relax and come back to their resting state. As you get older, some of that calcium that was lost from the bones will find its way into the artery structure and helps it lose its elasticity so we find an increase in blood pressure, even high blood pressure. We have arteriosclerosis. A result of this is the blood flow to the heart and brain diminishes. The valves within the heart become rigid and are not able to respond to the stresses of exercises as well as they once did.

Urinary System - at 80 years of age the blood flow to the kidney reduces by as much as 50%. Some of this information accounts for some cases of "senility". Because the blood isn't being cleansed as well as it once was, we have waste products floating around through our blood system which clouds our thinking. It is a kind of chemical imbalance that we run into.

These are some things that come about with aging. I hate to feel like the bearer of bad news. We need to be reminded that there are many things that can be done about this. Neil is going to relate to that a little bit. We can do a great deal to slow down the process. We can't stop the process. There is no way that we can stop the process. It is going to happen, more quickly in some people than in others because of the hereditary factor, but there is a great deal that can be done and that is being proven every day.

Look at people like Tom Cureton. I do not know if any of you have ever seen him. Right now he is a professor emeritus at the University of Illinois. All he does is travel and give lectures on physical fitness. He is also writing his own memoirs. After his lectures he follows up with an exercise class where anybody can join him. Both young and old can join him and if they can go to completion, it is to their credit because very few people ever finish the exercise course with him. He is 78 years old now. There was also Paul Dudley White, President Eisenhower's physician, who never felt that you were old until you were 80 years of age. Tom Cureton says he is going to live to be 150. In fact, he thinks he holds all the records in the 75-150 year old age bracket. He includes that all in one age bracket. But he has a very positive mental attitude and attitude is probably the most important thing along with activity.

Older Adults

Where fitness is a means, we get many benefits other than the fitness. We also get the social aspects of participation. I know what Neil is going to lead into, but in terms of fitness, whether you are young or old or handicapped, all fitness is really governed by about five different principles:

1. Overload - You need to do a little bit more than you ever did before to show improvement.
2. Progression - You need to do things gradually. You can't just jump in and expect to do what you did twenty years ago. If you haven't been doing it for twenty years, you'll have to start from the beginning and gradually increase your amount of activity.
3. The Law of Use and Disuse - If you don't use it you are going to lose it and that includes bone mineral and it includes muscle strength and it includes cardiovascular endurance.
4. Specific Activities - You can't expect to be a world class weight lifter if you are going to just run ten miles a day and not lift weights. The activity is specific to what you are trying to do with it.
5. The Individual Differences - Everyone is different and we have what we are born with to work with.

INCLUDING VOLUNTEERS IN YOUR PLAN

by

James Donovan
Metropolitan Board YMCA, Chicago, Illinois

We have been involved, in the last three and a half years, in a project that has focused on the development of both volunteers and staff related to volunteers. I think most of you are probably aware of the fact that the YMCA is a voluntary international human service, health and recreation agency. I was going to talk about the way the YMCA uses volunteers and I think I would like to rephrase that. I'd rather talk about the way we provide opportunities to be used by volunteers. I think this is a more appropriate way of looking at volunteerism. Unfortunately, many agencies like ourselves, get very much into the use of volunteers as a way of solving economical problems. As Mary Lou said, "Times have changed." Much has changed and that really is not the appropriate way to look at volunteerism. I think it has to be looked at as a mutual kind of venture so that we have something to gain with something to offer. The opposite is true that volunteers have something to gain from us and something to offer us.

In the YMCA we use volunteers in several different ways. The primary ones, of course, are to provide opportunities for volunteers to be board members, provide opportunities for them to communicate and participate in their community and the community that the YMCA serves, to give direction, to be able to provide services, to be able to get involved. In the same respect, you can give them the opportunity to become experienced in some new fields or new areas. You can give them some opportunities to do some service, to give some time, to relate to new and different people, and to grow and develop in their own right. I think these are the major efforts involved on both sides.

My topic was to talk about youth and youth as volunteers. YMCAs are particularly good in that area in that we have many opportunities for youth to volunteer. By doing so, we hope to provide them good positive experiences and opportunities. Of course, some of the more obvious ones are camping services, both day camp and residential camps. For years we have utilized youth as volunteers. We have Junior Leader clubs in all of our YMCAs. We have many classes and groups and youth groups that are led by young men and women. I think, though, that when you talk about youth as volunteers and involving volunteers in your plan, it is important to look at several different things. When we talk about youth, unfortunately we very often look at them as a cheap source of labor. I would hope that we would not want to see them in that way. I really like to look at young people as a natural resource and one that we would develop and protect just as our oil today. Needless to say, we don't put half the money into development of young people that we do in development of oil and energy resources and unfortunately, we don't see ourselves as doing that.

Including Volunteers in Your Plan

Have you ever looked at TV or any of the media and advertising? While we like to see ourselves as a youth oriented society, if we really compare behavior with our self image, that doesn't hold true. A study that was done by the New York Times several years ago showed that for every youth in the United States, we spent on the average of $500 per capita for education. We are spending, for that same youth, on the average of $8,000 per capita for defense. That kind of screams in the face of our image of self, of youthfulness and being youth oriented. I think that when we look at our own agencies and look at the times, we are looking at a time when we are providing many opportunities for young people to become acquainted with the world, to gain experience and opportunity, to help them make career decisions, to help them find their lives. The kinds of opportunities we can provide for volunteers, young volunteers, fill in some of the gaps and many programs nationally, locally, internationally, are beginning to look at the area of youth service as opportunities.

The CETA programs here in the United States are very much geared to be able to provide opportunities for young people to gain experience, become familiar with the world of work. How can we turn those opportunities into an even broader scope from within our own agencies, or how can we use our agencies and our programs to provide youth with those kinds of new experiences that will help prepare them for the future. As Mary Lou just referred to a minute ago, more and more legislation is being affected. Organizations and corporations are beginning to look at volunteer experiences in the same way we look at work experiences. This is going to be particularly relevant for young people.

I think another thing when we talk about volunteer opportunities, is the opportunity to provide, not just education for development and growth, but exposure to experience. One of the things that we would like to see ourselves doing, and we hope that we are always working at, and which this whole conference is about; is raising our own consciousness, challenging our own attitudes. Very often it is difficult for us as adults with very well formulated attitudes, prejudices, biases, assumptions; it is very difficult for us to change our minds. But when we are talking about young people, it is much easier to help them understand that differences aren't all that significant. We can give them opportunities to see people who are different from them; whether they be different physically, racially, socially, emotionally, whatever.

When we talk about mainstreaming, I think we need to talk about volunteers and contacts of not just youth who are not mainstreaming, or youth who are normal in whatever sense that word may mean, working with mainstream youth; but just the opposite. How can handicapped children or children who are somehow labeled as different, be given the opportunity to educate and help others. They need to help others understand that there aren't basic differences between them and help others understand new and different ways of looking at people. I think that that, in itself, is a service to society, to communities, and to both sides of the volunteer put together.

Another area is to look at differences in terms of ages. We find that using young people with senior citizens has been extremely helpful to the Seniors' programs. What hasn't been seen as readily is the fact that it has

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also been very helpful to the young people. Some programs were done in Minneapolis not too long ago where young children who were really rather trouble prone were allowed to work in some senior centers. They found out that not only were the seniors greatly helped by just having young people around, having new people to relate to and talk to, but they were helpful to the young people. The young people found that it was easier for them to talk with these older people than it was with their own parents. Somehow the generational skip seemed to open up a whole new way of communicating and helped the youth really look at how they might also look at life in different ways. Their own performance in school, their behavior with the courts and other places improved dramatically as a result of that effort. It is again an opportunity to use young people as volunteers when in fact they were getting as much back, if not more, than they were giving.

There are many examples like these, but if you look at the whole document that I am sure most of you got, in terms of guiding and developing programs and the categories in there; developing programs is really basically setting goals, looking at what you need in terms of human resources, physical and financial resources, relationships and processes, setting calendars, evaluating, etc.

You can go through each of those and really brainstorm for yourself ways that youth can be used. Youth can be used as board members. They can be used as planners. They have unique perspectives that none of us as adults have and particularly when it comes to program planning. Why not use them in those capacities? They offer a whole array of human resource opportunities for us. We can use them as program leaders and group leaders. We can use them as mentor to younger children. We can use them in terms of financial development. Young people do amazing things in terms of helping raise the money for programs. They can be anything from the most typical candy sales to more sophisticated things. Young people have done other things in the organization that is unbelievable in terms of the money that they have raised. Young people have walked miles for many causes. Unbelievable numbers of young people have raised substantial amounts of money as a result of this physical effort in going out and getting sponsors to sponsor them in doing things for money that they need for a new and different cause. You know why we have a whole international program and part of the international program is one aspect known as World Service. Young people have, for years, raised a great deal of money as part of that effort.

There are a lot of opportunities in the YMCA. I think it is also true in terms of relationships and process, that this can be used by youth to make the kinds of connections and links with other agencies, the school systems, with groups that they are part of and which they represent, and continue seeing it as a mutually beneficial effort.

INCLUDING VOLUNTEERS IN YOUR PLAN

by

Pamela Ransom
Director R.S.V.P., Chicago, Illinois

I have been asked to speak regarding the older volunteer so I have a definite bias. I am going to try and sell you on the older volunteer being the individual that you would like to recruit. First of all, I think it is important for us to take a look at some of the bias that we have in regard to older persons, both as a society and also personally.

Here we are talking about people 60 years of age or older which to me does not seem that old, but many times we think of older individuals as not being able to learn new things. They are considered to be stuck in their ways, not being productive. Maybe there is even a feeling that once people get older, automatically they are "senile" or they don't have the same mental powers of younger people. Well, I think that RSVP and our track record really dispels many of those myths. Last year alone we had 1,350 senior volunteers who were very active in their communities in a variety of services. As Mary Lou mentioned, it is no longer the stuffing of the envelopes and writing out lists and those types of volunteer experiences. There are very exciting things that people are doing. I think that just hours-wise, we have individuals that are not putting in one or two hours a week, they are putting in 40. You know they are enjoying what they are doing in addition to getting things back from our program.

As far as the RSVP (Retired Senior Volunteer Program), the goals that we're trying to accomplish are pretty much geared toward the senior volunteer themselves. We want to try to improve the quality of life for older persons in the City of Chicago. We are trying to provide volunteer experiences for individuals who may not otherwise be able to volunteer. Here again, it is not the upper middle class white woman who is doing the volunteering. People over sixty-five from all over the city are very interested in volunteering. We are able to make it more possible for them to volunteer since our program helps reimburse individuals for either travel or meals or any other out-of-pocket expenses that they may have. We also have several mini-buses that are able to take older individuals to the volunteer site if they are not able to take public transportation. Also, just the relationship, I think, between our community workers and the older volunteer is a very supportive relationship which I think is very important.

Another goal that we are trying to reach and, hopefully, it is what I am doing right here, is to dispel some of the myths about older persons, some of the stereotypes that we have. Lastly, one of our goals is to provide a good trained volunteer force for agencies within the Chicago area. I think this particular volunteer force has some real pluses. There is a vast amount of talent. The resources are just unbelievable. These are people that have had a variety of past experiences, knowledge, and are very talented individuals. How can the older volunteer be worked into a youth program or a program with handicapped individuals?

Including Volunteers in Your Plan

We have an exciting program called the "Living History Program". This program is intergenerational where older volunteers go into the classroom situation or library situation with schoolage children and tell them about history from their own experiences. We have a woman who taught in a classroom with a dirt floor in a small town. What was that like? We have a man who was an ace flying pilot in WW I. What was that like? Such people can really get across exciting things, make history come alive to young people.

We also have quite a few older volunteers who are working with handicapped youth. Some are working on a one-to-one tutoring with them. We have a gentleman who is teaching industrial arts or shop to a group of handicapped youth, mentally handicapped youth. A blind woman is teaching tutoring blind children in a Chicago school. So here again, it is a real variety of volunteer possibilities and I think there is such a vast resource within the elderly population that it is a good place to pull from.

We are also interested in talking about mainstreaming youth. We are also very interested in mainstreaming elderly handicapped individuals and getting them involved in a volunteer experience and that is going to be one of our RSVP focuses for next year. RSVP is nationwide. For people who are in the Chicago area, they could contact me at Hull House and I will be able to give them the office in their neighborhood.

INCLUDING VOLUNTEERS IN YOUR PLAN

PANEL

Mary Lou Thomson
Director, Voluntary Action Center, Chicago, Illinois

Thank you Beth. I thought maybe I would tell you a little bit about the Chicago Voluntary Action Center since I cannot speak for all of the VAC's in all of the communities that may be represented here. The Chicago VAC started in 1943 at the time of the manpower crunch during WW II, and evolved into a clearing house for volunteer manpower. That is, recruiting volunteers, interviewing and screening them and then referring them out to agencies in the Metropolitan Chicago area that are utilizing volunteers.

We now really are an agency's agency. We are a training and consultation agency concerned with effective management of volunteer services. We still do some referral for potential volunteers to agencies, but it is a very small portion of what we do and a rather low priority for us. We would rather work with you, those of you who are in agencies using volunteers, in helping you recruit volunteers, helping you develop volunteer programs and develop recruitment programs that will affect your specific program. Obviously, we can not, nor can any Volunteer Action Center, recruit all volunteers that are needed by all of the agencies. In Chicago we are talking about 15,000 agencies. We can't tell 15,000 stories. You can tell your story better than anyone else and we are in a position to try to help you either by working directly with you in a consultation role or by identifying those specific needs that are represented in the Chicago Metropolitan area, either by clustering agencies utilizing volunteers in similar kinds of positions, or by identifying gaps that are needed in volunteer manpower and then designing a promotion in a metropolitan area which would highlight those specific kinds of volunteer opportunities.

We are also developing training programs for staff on effective management of volunteer programs. We are working with specific agencies in developing volunteer programs or training programs for volunteers. We got out of the business of training volunteers per se, feeling again that this is the responsibility of the agencies. You know where the volunteers are going to be utilized and you know how they are going to be used.

In the Minneapolis and St. Paul area there are two active Voluntary Action Centers and they are both very similar to Chicago in the kinds of services that they offer. Indianapolis has an excellent Voluntary Action Center. Flint, Michigan, also has a Voluntary Action Center. They are all very much involved in training and consultation services for agencies. In most cases we work for not-for-profit agencies, but not exclusively. We also work with State and Federal agencies and in some cases with proprietary agencies. For instance, if there are nursing homes or senior centers that utilize volunteers, we are concerned that a volunteer isn't being utilized or exploited in a position that might increase the income or profits of an owner.

Including Volunteers in Your Plan

Who is this volunteer? I think for the 1980's we have a very different kind of market. Agencies are offering many different kinds of opportunities for volunteers and there is a very different volunteer out there who is looking for experiences. In the Chicago area, in the four years we collected data from a sample of agencies, we found out some interesting things which helped us predict some trends: The highest percent of all the newly recruited volunteers in the Metropolitan Chicago area are between the ages of 18 and 29. The largest percentage of them are students and/or employed professionals. This is the newly recruited volunteer. The woman, the middle-aged, middle class white woman, is still there, but she is losing ground very rapidly to younger people and to employed professional people and men. Nationally, there are statistics that show that 40% of all volunteers are men. (I am not totally convinced that this is true, but there are figures that show this.) I think the fact there are many male volunteers involved in the criminal justice system, on a one-to-one basis with young children such as big brothers, has probably helped increase the number of men.

There are figures that show that 12% of the volunteers nationally have incomes under $4,000 a year. Pam will tell you later the kinds of programs that are reaching the lower socio-economic and retired populations. We had a 900% increase in volunteers recruited who were 65 years of age and over during that period in which we collected data. Many are older people who are retiring, healthier and want to stay involved in their community. There is a large percentage of volunteers who now represent a constituent group or a group of people who used to be only receivers. They are now "givers" and some of those people are here today representing both physical and mental handicaps. This group also includes those people who have gone through drug rehabilitation programs or are ex-offenders and are now on the other side and helping ex-offenders when they first come out. There are an enormous number of self-help groups in America today.

Corporations are now very much involved in the volunteer community. They are involved because of pressure to take the responsibility for the corporate dollar to get back into the community, rather than to simply increase profits for the corporation. Corporate executives are working closely with us in the larger urban areas, in employee involvement and corporate volunteer programs. For instance, Allstate in Northbrook, their national corporate headquarters, have volunteer employee committees that determine what kinds of programs and agencies they want to work with. They then recruit employee volunteers and work in a fairly organized year around program.

There are many other kinds of volunteer opportunities, so the market that you have out there is not as easy going as it used to be. If the volunteer in your agency is not having a good experience, all he has to do is walk across the street to find a different kind of opportunity. A very different person is in that "volunteer smock" now and he is also out there volunteering for some very different reasons. The volunteer's motivation is not entirely altruistic any more. They no longer volunteer just because they want to do something for the community. It is very likely that they want to do something for themselves and what this says to the agency is that it has to start keeping good records

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because volunteers are getting involved because they want experiences that will help them in searching out a new career. Employment credit is now given by the Federal and the State Civil Service and many corporations are now looking at volunteer experience as just as valuable as paid experience. Agencies must have records that will substantiate the kinds of experiences volunteers have had. If volunteers want experiences that will help them, then envelope stuffing and similar kinds of experiences may no longer be interesting or acceptable to the new volunteer who is younger and career oriented and looking for other kinds of experiences. Volunteers also want to be involved in an agency that has credibility and accountability. If it is a federally funded program, they want to be sure that what they are doing is legitimate and is helpful in meeting needs of the community, of the client, and accountable to the funding source. I think all of those things are very important for you to remember when you are looking at the volunteer in the community today.

Including Volunteers in Your Plan

Questions and Answers

Beth: What we have really tried to do is just touch on some of the issues that involve volunteer participation and I see that people have brought materials with them. We want to throw it open to you for a minute. Do you have questions or comments that you would like to make, maybe about volunteers that you have in your agency or participation that you would like to see happening?

Question: Is there anyone here from Girl Scouts? They did research about two years ago that showed that many of the volunteers that they recruited they were able to recruit only on a short term basis, maybe for six months. I was just wondering what the follow-up to that was. Do you know anything about it?

Beth: I'm not sure. We worked with the Girl Scouts in taking a look at some of the kind of ingrown problems that they had. For instance, if you have a program where you are going to be recruiting and utilizing parents, that program is going to have a high turnover rate simply because you are recruiting them to work while their child is there and when the child leaves, the volunteer is going to leave. Do not panic at the fact that you have a high turnover rate. Build your recruitment program and build your support system so that it works with it.

Another thing that the Girl Scouts have been doing is to team volunteer so that you are not throwing all of it on one mother or one volunteer. You give the volunteer support. The volunteers simply do not have the motivation there to give an enormous chunk of time. They don't have that kind of time. They are not as interested in long-term commitments, they want short commitments. Recruit two people to do that job, ask them to be co-leaders or look at the job and split it up so that it is not as big a chunk for one person to chew. If you are going to have employed, young professional people; they want jobs, they want smaller units, they want small pieces, they want gratification. They want something that they can handle and move along with it. I think that is part of the study the Girl Scouts has done and there is indeed a great deal of material that will be extremely helpful to you.

We have a resource center as most voluntary action centers do. It is a repository for national studies, for statistics, for materials that you can either take a look at or you can order and use. I brought some and it will be available for you to look at after this is over. There is a great deal of experience from all over the country that I think we need to take advantage of just as what the Girl Scouts are learning can certainly be used by other agencies.

Comment: I thought it would be good if we had each one of the people who were involved in some of the sessions we had just prior to this, make a comment on how they use volunteers. I could open up a little. I think one of the things that I found the most helpful in working with volunteers, in the different agencies that I have been involved with, is being honest with the volunteers as far as the commitment and the time. We used to be very lax and say, "Well, this isn't going to take much of your time and don't worry about it." We would lose them faster than we could recruit them. Tell your volunteer that the work will take four hours a week or two hours a week and that is what is expected of them. Thus, you are giving them a job description or position description related to the responsibility of being a volunteer to this program. Again, I think when you are up front with people and are honest as far as the kind of commitment you expect from them, your cooperation is going to be much better.

Beth: Some agencies are even asking for contracts and are getting them, an absolute contract just as though you are employing someone.

Comment: To go one step further, a more personal example, one of my last responsibilities before coming to Chicago was opening a brand new YMCA which originally had a budget of about $8,000 set aside for staff. When the building was opened, there was nobody. It was totally run for a year by volunteers through the recruitment process and training process.

Beth: One of the things we are going to do tomorrow is look at recruitment. A part of that is how to develop job descriptions so if you are interested in looking at some specifics on that, please be there.

Comment: I am from the Leaning Tower YMCA. We have half and half; half adults and half children as volunteers there. I think one of the biggest things in keeping them is building rapport, saying things like "I don't know what we would have done without you." It took time because it is, usually, "Class is over, goodbye." All of a sudden all these new volunteers weren't there anymore. Suddenly it sank in that you have to say, "Thank you." It is not a party once a year, which we have anyway, because they are not going to be there by that time. Every day you go out of your way and say, "Thanks a lot for being here."

Beth: Excellent point.

Comment: Another interesting point we have learned in recent months is that, as Mary Lou mentioned, the age of the current volunteer population is going down. She mentioned 18 - 29 as the age range of the majority of volunteers today. An interesting phenomenon of that age group is they represent a different value system than some of us may be familiar with. Some of the characteristics of that value system is that generally speaking, they seem to have a higher need for "immediate gratification." They seem to have a higher need for self-fulfillment, whatever that means. These all contribute to the kinds of things that you are saying. They cannot wait until the year end and the party or recognition event. The importance of letting them know how they are contributing in a very direct way is going to be a very important aspect in keeping them as volunteers.

Comment: Such an inexpensive way to keep volunteers. Two little words, "Thank you"!!

Beth: There are many ways to do that. There is another way and that is promotion of the volunteer into more responsibility. People say you can't promote a volunteer. You can and you know, sometimes I hear someone say, "That volunteer has been on that desk for 17 years." and

I think that is terrible. I don't think that is what the volunteer really wants to do. Giving that person more responsibility or a promotion into another job is another way to do it. Let that volunteer become a trainer of new volunteers, let her help you in supervision and other ways. There is a great deal of gratification that comes from that.

Comment: That's right. "They chose me to come here.", I mean they were really flattered. Theresa came and helped Ray in the gym. She took off work, she could have been paid, but it was very important for her to be here.

Comment: I am really surprised. I think you are all aware of the Red Cross Youth Group and the way they are trained. They are excellent and one thing that they will not do is prepare for parties. I tried to get them to come to prepare for parties, but they said they went to volunteer to help the people and I thought it was so beautiful. I had them once for a group. The handicapped put on a concert a few years ago and had them for the whole day. We had a marvelous concert. I had about twelve of them and six were faithful to the wheelchairs and stayed with the wheelchairs. I was looking for the other six. I couldn't find them because they were back in the kitchen cleaning everything up. I said, "Go to the concert, enjoy." They said they came to volunteer. I think we should propagate that youth group and let people know about it.

Beth: They do an excellent job, by the way.

Comment: I might say too that the Red Cross, more than most other voluntary agencies, in the true sense are more voluntary than most of us. They have a higher percentage of non-paid staff than any other agency I know of. They also have one of the best inhouse training and training service programs than any of the agencies have.

Comment: I believe that the reason is the attitude toward their volunteers. I think the way they treat them, the way they speak to them, they make them feel that they are wanted.

Beth: Good point.

Comment: They have a social justice program. I have two of their boys helping me. In their senior year they sign a contract and they have to be at the place where they are assigned. They are some of the best volunteers. They are there every day and another thing is that my programs occur during the day. They arrive from 2:00 to 6:00 when it is hard to get volunteers. They have to make out their report cards, they have to keep their attendance, and believe me, they never miss a day. Sometimes when you get these high school boys and girls, they make a dating service out of it. I would have to kick them all out.

Beth: I think it does come back to what your expectation is of your volunteer and then maintaining that and what you are saying is very critical in that.

I think one other thing they are saying, though, does bring up one of the new issues or one of the new resources and that is experiential learning that the schools, the high schools and colleges are now emphasizing and it is a marvelous resource for you. There are schools that have volunteer coordinators, volunteer service offices, and it is marvelous. I would also like to pick up on something that Jim said when he was talking about youngsters as volunteers. One of the best that I heard of recently was a school that had second graders tutoring first graders. It was a terrific program and nobody was quite sure who was getting the most out of it. The only criterion for the second grader was that he had to be one page ahead of the first grader in reading. It was a tremendous motivation for both of them.

I think that we really do not see some of the obvious things in front of us. Neighborhood houses have senior centers and head start programs in the same place. They are screaming for volunteers and they do not look at the Senior Center as a potential resource for the head start which is so good for both of them.

Another program that I heard of is in a small town in Iowa. They had a high school gym teacher who was a very innovative, creative man who had a real problem with high school kids who really were dropping out because of their aversion to the standard type of gym programs. It was really turning them off. They were not many blocks from a retirement home and they got the two together. The high school students were turned into an alternative type of program to develop exercise classes for the people in the retirement home. It was so exciting because it was intergenerational and it was meeting two real needs. It was an extremely exciting program.

Comment: Some of the finest volunteers are high school boys and girls who are associated with the Key Club. I'm a Kiwanian and I'm the Kiwanis advisor to said High School Key Club. Their major emphasis program is a program I have on Saturday afternoons at a church. I have 22 Cub Scouts in the program. We just started it a couple months ago and it is getting along very well with volunteers. If anyone wants to get in touch with a Key Club and the volunteer program, they are the ones to reach. They have their own program and it is a major emphasis program because they get credits on their volunteer work. It is really wonderful to have them and they are really outstanding students.

Beth: Thank you. There is a good recruitment tip for you.

Comment: In our community, St. Remus Church has as part of their confirmation a 6 - 10 week human service type of program so I do get several kids from there.

Beth: That six to ten weeks is great. It's where they want three hours of service that sends the agency up the wall.

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Comment: But I found that the kids at the age, the boys were much more responsible in coming regularly than the girls because of the social aspect. You know, the girl relationship was developing beautifully. At that age the boys were not, they were more interested in really working with the student versus associating with the other volunteers. It can go either way, but we've had them regularly for about two years now, three to six at a time, and we have to keep all the records for them so they can bring this data back for their confirmation.

Comment: This is a different aspect of volunteering. What we did was take $10,000 out of our budget for a Control Center person who is at the cage and we also took about $5,000 out of baby sitting and about $4,000 out of reception area in our budget and put it to volunteers. Young married couples, single parents, and also parents with young adults who can't afford to join the YMCA can earn their membership. They sign in and sign out on a payroll, but we don't pay them, it is a bartering system. They can earn their membership by the minimum wage and we have found that quality has improved in all areas. We have women earning memberships for their families. One woman types 85 words a minute - where do you get something like that at minimum wage? The quality of baby sitting has improved. As a result of the bartering system, we have been able to get some very good people. It is a mutual help thing.

Beth: I just hope that you are keeping good records because references for volunteer work that has been done well and done without a monetary reward is the best payment that you can give and a marvelous recruitment tool; particularly for college, the career, and the experience that they are getting in doing this.

Comment: One other one. We did this in cooperation with churches in DePage County. We explained to the people in the churches what some of our needs were and they recruited volunteers so we have about 200 meals delivered every day to homebound people without any exchange of money at all. People do this. The other thing that churches do in working with their own membership is to recruit the volunteers to teach some of the activities that are being held. If you talk to other non-profit groups including churches and the ministers and priests, you can recruit with them.

Comment: Another point that I would like to make that we haven't really talked about directly is how well do we really reward and motivate our staff who are particularly good at working with volunteers. Time and time again, I look at our former three years in the Y and realize that our program staff are measured on how many classes they do and how good they are at their budgeting and fund raising, but very seldom do we significantly look at the importance of a staff person who is particularly good at working with and keeping and developing volunteers. That should be a key factor in terms of how well we are operating our organizations and how well we are working in our communities.

Including Volunteers in Your Plan

Beth: There is only one agency that I know in the Chicago area that is actually doing that and that is Children's Memorial Hospital and they have that as a part of their staff performance rating. The number of volunteers that a staff member is supervising is commensurate with their salary. Thank you for saying that because it is something that I have written into the vast five-year plan for the Chicago area so that there is recognition that it takes time, effort and enthusiasm to not only get volunteers involved, but keep them, retain them, and we've got to do the same thing with staff who are doing it.

Comment: I wanted to bring it back in perspective before we leave. Do we have a rational recruitment program for volunteers:

1. In the light of Volume II (Mainstreaming - A Guide to Developing a Program), we are going to have a series of job descriptions that are in the backs of our heads, if not in writing, with some concepts or functions for them.

2. We ought to have some kind of a skeleton as to the type of person to meet the needs of a particular job.

3. The volunteers should be broken into two groups; those that are going to serve short term (a unit leader or a program deliverer of the program, etc.) and the support people who have an entirely different characteristic. In Boy Scouts, for instance, our merit badge counselors have to be long-term people. They are the ones who really give. We can recruit a parent to run a cub pack while their son is in the program and we accept this as a variable labor force, but the hard people that are going to coach them, the hard people who are going to support the program, these have got to be long term.

Jim: I have three things I want to share with the group. One of the materials that we have developed in the last four years is a manual for the staff which is called, Helping Hands Achieve Success. Although it was written for YMCA's and YMCA staff, it is applicable to any agency. Basically, it is a "How-to" manual for staff in working with volunteers and in it there are several sample job descriptions and a sample format to develop job descriptions. There is also a hands-on kind of tool. It is like a simple contract, how you can negotiate a contract with volunteers, samples of various reward and motivation systems and some ideas on that.

The second one is put out by Volunteer of the National Center for Citizen Involvement, and they put out this pamphlet every year which is called The Volunteer Readership. This is their most recent publication and in it are about 20 pages of various resources related to volunteers and volunteerism.

Third, there is an organization called National Commission and Resources for Youth. It was founded and is currently operated by a retired Juvenile Court Judge by the name of Mary Conway Koller and located in New York. National Resources for Youth puts out a newsletter and several different materials which catalog all kinds of model programs utilizing youth as volunteers. It is an excellent set of resources related to ideas and samples, programs and models being done all over the country in different ways to use youth in very innovative and creative situations.

VOLUNTEERISM

by

Beth Broadway
Metropolitan Board YMCA, Chicago, Illinois

I think that one of the things that we can do this morning is to hear some things that you are involved in rather than having me tell you how to do something. I think that we can learn from each other and maybe facilitate a process here where you can look at the kind of people you want to recruit in your program. From this you can develop some of the job descriptions that we have mentioned. It is critical to know specifically what it is you want from a volunteer before you step out the door of your agency and begin doing that recruiting. We also wanted to take a look, after we take a mental trip through our agency, and see some of the opportunities that might be available there for volunteers that we are not now staffing that way. We also want to take a look at some of the things that block volunteer participation and some of the things that facilitate volunteer participation. Being aware of those things and being aware of how you impact on all of that can be critical on whether or not people are recruited properly.

I think we got an overview last night of who the volunteer is. We heard that the volunteers may come from all sections of the population. It is not only, as we said, the traditional middle class woman who is not working outside of the home. There are a multitude of people who are volunteering and many of you substantiated that when we talked last night. We have many youth who are working as volunteers, many men who are volunteering. There are many service groups who are doing things as a total group for agencies. It isn't limited any more to a particular kind of person. I think that came out last night at our panel discussion.

What I would like to have you do is just sit back in your chair for a minute and close your eyes. I want you to relax for a minute and I would like to have you take a walk through your agency. If you are a small agency that has a storefront and just an office, what I would like to have you do is walk through your programs. Now, close your eyes and begin taking a look at the kinds of services your agency is offering. Take a look as you walk in the front door at what is going on there. What do you see? If you have a hallway, walk down that hallway. Are there offices off to the side? What kind of activity is going on in there? Look also at some of the things that volunteers could be doing in these places. Begin to think about all of the jobs that volunteers could assume. If you have a pool, walk down to the pool. You have classes going on down there. Where could extra hands be used, extra eyes? Walk into your gymnasium area if you have one. Where could volunteers be used there? See that child, off by himself, playing on the equipment, unattended? An extra pair of eyes could help there. If you don't have these facilities, walk through some of the programs that you are offering. Do you have bus service for handicapped individuals? Do you have some kind of recreation program where you are using city facilities? Think about all the potential use for volunteers. Open your eyes slowly and come back to us. I would like to have you take a minute to brainstorm lists of all of the jobs that you think volunteers might do. Quickly write them down.

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After you have made your list and some of them have ten to twelve positions, run your eyes down that list. If you were able to go back to your agency and begin developing one of those positions, what kind of volunteer would you want to fill that job? Which one would it be? Key in on that. Does anybody want to share the job that they would start working on - the title of it?

We are open on Sunday now. I have four seniors every Sunday who come to the Y from 12:00 to 5:00 and they lead tours. We have YMCA swimming, a tour of our facilities which takes about 40 - 45 minutes. These people did a beautiful job. They do our checking for us. They do all of our bulk mailing as well as other things. Maybe doing the mailing is an unimportant job to some people or it does not seem that necessary, but we get out from 5,000 to 8,000 brochures at a time, maybe even more. There might be forty to fifty seniors in a room all talking at the same time and doing the bulk mailing. I think that it is very important for them because this is their Y. They do baby sitting. They do anything that you want them to do. You will see at least five, six, maybe eight seniors every day coming in and doing something.

I would suggest, as you develop a volunteer program and look at how you are going to recruit them, that you match up what the volunteer has to offer and wants to give with the kind of need your agency has. It is not a one-way street, "I need this; therefore, you do this." You need to find the person who wants to do the job. That is how you keep a volunteer.

One of our men is a retired printer and he does a lot of our printing for us, brochures and things that we have, then he puts it up. We have a central bulletin board and whatever is going to be going on, we put it up. Yesterday I said that I needed a number of seniors and that everybody who wanted to come should put their name down. I don't say, "I want you and you." I say, "Whoever wants to come, you are welcome." I think that maybe it isn't that important to do the mailing for us, but you realize the camaraderie that is going on with all these people. Their only stipulation is that they are supplied coffee, drinks and coffeecake or cookies because they love to drink coffee and eat. Well, what could be better than to see them all sitting there busy and talking.

If you put any one of those people in a room by themselves and said, "Here do this, do that," it wouldn't happen the way that you are saying. What you are doing is saying that the people that were coming in want to belong some place where they have a place that is theirs. They call it "My Y", and that is how they feel.

What I would like to share with you dovetails with what we are talking about which is finding jobs that we think that we have a need for and also finding the kind of people to fill those jobs which will be meaningful to them. One of the things that we talked about is developing a job description. What I would like to share with you is just a sample outline for doing that. Let me pass this out to you and run briefly down it.

When we initially developed the job description for volunteers, it omitted Section F. More and more as I have worked with staff like yourselves, I am hearing that it is very critical to find out what it is that is going to motivate the volunteer in being a part of our team. Some of these things are

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the way they are supervised, the kind of training we provide for them. Do you have the Helping Hands Manual? What we have done with the job description is add a section for not only what it is we want the volunteer to do and the kind of experiences they have to have, but also the kind of things we will provide for the volunteer in the course of their work. It is not just what they are going to do for us, it is also (in Section F) what are we going to do for them.

I think that the mixture of those two things is critical in developing a job description for your volunteers. Jim Donovan pointed out to us last night some of the things that he is doing. There is a bartering system going on at his Y and I think that is a fascinating idea. Some of you may want to talk more in depth with him.

This may serve you as a guide for developing some of these jobs that you would like to have volunteers do. If you have volunteers who are already doing something like this, they might be able to write the job description for you rather than have you write it. Writing a job description would be something that a volunteer does so that your program can go on. A job description provides a continuity for you.

VOLUNTEERISM

by

Joe Agnello
Training Director, Volunteer Action Center, Chicago, Illinois

You have already talked about who volunteers are. I had intended to do that this morning so I thought maybe I would just hand this out anyway. Along the left we have a profile of who volunteers are, "People who are volunteering." This was done from a study in Ohio and it is comparable to studies that were done in the mid 70's. I think the statistics are pretty good. If you look at it, what do you notice the most about those percentages on the left? What seems to stand out? What does that tell you about the volunteers?

Start with No. 1. What does that tell you? It says volunteers are mostly white women. What else does it tell you? Most are under 40. Most highly educated, bored at home. What you are saying here, the implications that you are deriving from these statistics, this profile here; these are common myths about volunteers. Now, in fact, these percentages are accurate, but the distinction is that this profile could be the profile of any population of Americans because there are more women than men - 60% women and 40% men. As far as whites and non-whites, these are accurate perceptions. These are accurate statistics so people conclude that women volunteer more often than men. That is actually not true at all. but where the myth leads you is that it makes you look for women to volunteer more often than men. That is where you would be going wrong. Do you see that?

Now look at the percentages on the right hand column. Within that category of men, 54% are volunteering. Of all women, 59% volunteer so the percentages pretty much hold true that men are as likely to volunteer as women. 59% and 54% isn't much of a difference. That is what that statistic on the right is telling you. As you go through you see that people feel that blacks don't volunteer which is actually not true at all. They are just as likely to volunteer as whites - 57% whites volunteer and 56% of the black population volunteer. That is all it is telling you. Just because there are more whites does not mean that whites are more likely to volunteer.

As you look at No. 4 you'll see that education does seem to have an impact on volunteering. A greater percentage of people with some college, more than a high school education, tend to volunteer. As education goes up, their likelihood of volunteering is also likely to go up. The implications for that might be that when you are looking for volunteers you might look for people who are educated, they are more likely to volunteer. That is the only difference there.

In terms of age, you can see that the older people get, the less likely they are to volunteer, but that does not mean they are not going to volunteer at all. A high percentage of people with children under 17 seem to volunteer also. I was going to give you a bit more information about how you could start targeting in on these different groups.

Audience: It is hard to believe that 16% of all the volunteers in this study are homemakers.

Agnello: If you take a look at the percentages on the left, what it is saying is that out of this whole sample of volunteers that they studied, 16% of them were homemakers. If you look to the right when you look at the whole community, in that whole community, 56% of all the homemakers in that whole community are volunteering.

At any rate, you start taking some of the myths and start targeting in and having a more accurate perception of who is volunteering. Then the next step is to start taking a look at what your needs are for volunteers and target in on various specific audiences.

On this white sheet I have listed a number of ideas that I think you should take a look at in terms of your own recruitment capability. From this you can start looking at areas. If you feel this is appropriate for you to concentrate more of your attention on, in terms of organizing your recruitment campaign, this is like a check list to examine where you are at in terms of recruiting volunteers and the capability the organization has in recruiting volunteers. If you look through this, do you have any questions about that? Why that would be appropriate or necessary for recruiting volunteers? This should have gone first. You modify it for your organization, but they are ideas to stimulate your thinking about. How are you organizing your recruitment efforts?

Audience: I think for those of us who have staff recruitment procedures, #17 and #19 are extremely important. Otherwise you are going to perpetuate something. You have to stop and look at what you have, look back and see what is happening.

Agnello: What do you do in your organization to collect that kind of data?

Audience: We keep some pretty accurate records of those who sign up for another year. We do, supposedly, when they leave, put down why they are leaving. Now that is not mandatory, that's why I said supposedly. As in industry, turnover of personnel is terribly expensive and time consuming. You have to train people all over and by the time they know what they are doing they are out the door. Unless you look at why they stop volunteering or why they terminated, all the techniques in the world aren't going to get you anywhere.

Agnello: You are absolutely right.

Audience: You take 20 questions and apply them to the employed person. It is not very common to find an employer that assumes his workers are going to work voluntarily. They assume they are going to work as long as they are given orders to work, right? Isn't that the assumption? That they want their paycheck?

Agnello: Your best recruitment strategy is having a good program. There is nothing better than having a good program. It is the program and the opportunity of providing that kind of service that volunteers come for in the first place. It is the situation itself that will keep them or make them leave, but it is not what motivates them. A good program is what will keep volunteers.

The yellow sheet you have is a way for you to organize your thoughts if you can do that in one minute. I put together a calendar and the little boxes are categories for you to conceptualize your plan. It may take twenty to thirty pages to do this if you want to do it thoroughly, but once you put together a plan and a staff of volunteers and paid staff that are going to work on that plan, there is no way that you are going to miss unless your paid part-time staff feels the overwhelming power of the very strong recruitment of volunteers. One of the principles that is one of the key problems in volunteerism today is that programs that work with volunteers, almost all of them tend to have paid staff. What happens is that volunteers come in and do the very same work that paid staff are doing. Wasn't that why we had a Civil War in this country a hundred years ago when the union workers in the north who were working for very minimal wages had no future to look forward to? Slavery was going to take place in the north as well as the south. The union workers had to compete with slave wages. That is why we had a Civil War. This is with us today when we are competing for wages, but in this particular case, we are competing with people who are not even going to take any wage. It is a particularly serious problem and it is one that you all have to be conscious of. A good plan will give consideration to the fact that the paid staff feel threatened. You must work in ways and roles in which volunteers have to meet roles of contributing that don't compete with paid staff.

Audience: Can I throw in a comment? Often your volunteer is a much more dedicated person. He works long hours.

Agnello: You mean sometimes the volunteer is more enthused about the work than the paid staff?

Audience: The volunteer does not feel obligated to come unless he wants to and may stay home, perhaps if it were snowing. I saw it was snowing and I came. It took me two and a half hours to get here. I don't think your average volunteer would have come.

Agnello: I will give you one indication why volunteers are often highly motivated where paid staff are not. One reason I see this happening very often is that just like this, when we are talking about organizing a good program for volunteers, we find that volunteers get really good training programs. How many of your paid staff in your program in your departments go to training as often as your volunteers do? In the YMCA you have a more formal structure for training than other programs, but what I see most often is that, in agencies, volunteers get extensive training, and paid staff gets minimal or no training whatsoever. There is a great deal of attention paid to volunteers because they are concerned with an emotional pay check. With paid staff we often find that simply because we are buying their time, we don't feel we have to concern ourselves with their needs as well. I am not saying that that is true all the time. It certainly isn't true all the time, but I do see it happening very frequently. Yesterday twelve seniors came and they said, "I promised you we would come" and they really didn't have to because the weather was so bad, but they said, "Oh, we want to."

There really aren't any major differences between volunteers and staff. Some staff are highly paid and highly dedicated and others are poorly paid. You know there must be something that draws them to their work. They must really enjoy their work. Frequently there is a polar difference between volunteers and paid staff. How do you handle it? This can be done by team building, many staff meetings that involve staff and volunteers. Training sessions that are available to both paid staff and volunteers. You should not treat your professional staff as though they were at a status level that is particularly much higher than the volunteers. The status is the same.

There really are many approaches. There is a book by Ivan Schire that just came out last year called, "The Recruiting of a Nation". He spent a chapter dealing with this kind of problem. He talked about organizing job descriptions that do not compete with paid staff. For example, there are many, many dimensions. He mentions ten of them, but there are many dimensions where there is a unique difference between what volunteers can do and paid staff can do so why put them in the same category? In terms of advocacy for clients, there are many things that volunteers can say simply because a pay check isn't held over their head, that paid staff could never say in terms of advocacy for their clients. Even at this point, in terms of planning your recruitment effort, some volunteers should be involved, perhaps a board member, someone at a policy level.

Audience: Often it is critical that we allow some of the negative feelings to surface. Sometimes, getting those things on the table and having a session where people do talk about these things, opens things up. It may not solve the problem. I think we don't do enough attitude building with our paid staff to support the volunteers because there is a threat.

Agnello: In terms of planning, I would like to just highlight a couple of points. First of all, examine what you are doing in terms of volunteers right now. That is very important. Across a period of time, January to December, take a look at very specific target audiences. Figure out whom you want to approach in your community. Whom do you want to approach in each of these different communities? Then decide on the techniques you are going to use, the frequency with which they are going to be used each month for each target audience. The pattern in which volunteers tend to get involved follows a bi-modal curve, the very same curve of the business cycle which has a peak in the spring and a peak in the fall. It is going to dip down in the summer. Plan for that because you know April is going to be a great month for recruiting and so is October. Those might be the times when you will want to do one great big solid blitz. Go out there and really talk it up among your volunteers. Get them to bring in their friends. Do a great deal of promotional work on television, radio, getting many posters out. As a matter of fact, if you do nothing more than that,your best plan would probably be to have two very, very strong recruitment campaigns a year and the rest of the year just concentrate on keeping the volunteers that you have. You must be sure that they are paid attention to and they are involved in work. That probably is the best strategy of them all, rather than concentrating on recruiting many times through the year. Twice a year make a total organizational effort to bring volunteers in and the rest of the time be concerned with your program so that volunteers stay in the program.

What we had intended to do was take a look at recruitment problems, take a look at things that facilitate recruitment, and then we are going to build some strategies. However, my name is Joe Agnello and I work at the Chicago Voluntary Action Center. My phone number is 782-2870, Ext. 232.

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Comments

by

John Sullivan
Superintendent, Friendship Facilities, Ottawa, Illinois

John Sullivan discussed at length and in considerable detail the problems relating to placement in sheltered workshops and activity centers in local communities. He discussed the lack of acceptance because of personal mannerisms and the hassles with IRS and labor departments over pay scales.

He stressed the facts that mainstreaming can best be initiated at a young age and that communication with and reliance upon the leader are of greater importance than with any other contacts.

Laws relating to placement in independent living homes, half-way houses, intermediate care homes and others need to be changed and the speaker urged agency people to lobby for these changes.

Various evaluation tools to be used prior to placement of a disadvantaged person in a facility were displayed and discussed. A kit distributed by EPS Company was highly recommended. Another recommendation was a series of film strips including "Learning About Mental Retardation" and "Introducing the Mentally Retarded." The McCrea-Diaz Evaluation kit (University of Texas) received high praise.

Constant observation and informed counseling must be maintained.

When disadvantaged persons are placed in foster homes, the families must show empathy.

Trained evaluators are sorely needed.

Although disadvantaged persons tend to be highly conscientious on the job, it is a mistake to assume that they do not become bored and disenchanted.

He stressed the fact that agency personnel have the opportunity and responsibility to develop the capabilities of independent living by handicapped individuals. He closed by describing the independent living arrangements in a situation with which he is associated.

Quo Vadis

by

William P. McCahill
Boy Scouts of America

We have been talking about mainstreaming for three days and I'd like to share with you a definition from Frank Bowe's very excellent book, Handicapping America. What is mainstreaming? As was the case with individualized instruction a few years ago, no one seems to be able to come up with a satisfactory definition. Perhaps the 1976 Delegate Assembly of the Council for Exceptional Children defined it best. Mainstreaming, CEC decided, is a belief, not a method. It is a belief which involves an educational placement procedure and process for exceptional children based on the conviction that each such child should be educated in the least restrictive environment in which his educational and related needs can be satisfactorily provided.

This concept recognizes that exceptional children have a width of special education needs, varying greatly in intensity and duration; that there is a recognized continuum of educational settings which may in a given time be appropriate for an individual child's needs; that to the maximum extent appropriate, exceptional children should be educated with non-exceptional children and that special classes, separate schooling or other removal of an exceptional child from education with non-exceptional children should occur only when the intensity of the child's special education and related needs is such that they cannot be satisfied in an environment including non-exceptional children, even with the provision of supplementary aids and services.

Mainstreaming so defined, Frank Bowe says, is breathtaking in its implications for educational programming. It is also unlikely to become reality for most disabled children for several years, and this was written three years ago, unless and until America recognizes disabled people as individuals deserving of equal opportunities. This group, over the last three days, has demonstrated that they are committed to equality, not only in education, but in other areas.

Quo Vadis was a book written about persecution in the early days of Christianity and the word itself, from the Latin, means, "Where are you going" or, "Whither whence", if you want to translate it as a slogan. Where are you going? We are all going to Indiana, Ohio, Illinois, Michigan, Wisconsin, Grace and her friends are going back to Washington State, I am going back to Washington, D.C. and we are going back to whence we came. However, that is not what the quotation means here. What are you going to do? What this really means is that after having spent the better part of these three wonderful days here, what are you going to do? In the book Quo Vadis, the Christians eventually manage to win the battle and Christianity became the rule in the Roman Empire. In our own battle, the handicapped have won some battles, but they have by no means won the war. We are on a pilgrimage or a journey. We are going somewhere and it is my job to sort of run you through the last two and a half days.

Quo Vadis

At the beginning we had Dr. Julian Stein talking about myths and realities and Daryl Jenkins, John Sullivan and John Sevier reacted to that. We heard Julian tell us that today was important and if we cannot do it today, then certainly we can perhaps do it tomorrow. Probably the best statement he made which stayed with me is that a difference is only a difference if it makes a difference. This I think you might want to take with you back home.

We heard the word 'continuum' used not only by Julian, but by several other professionals. He also said that in work with and for the handicapped individuals, we have to continually ask ourselves, "Is this for the benefit of the participant or for our own benefits or the benefits of our organizations?" That is a rather hard question sometimes to answer because it is not an either/or. It is frequently both and hopefully it will always be both. It has to be at least a 51% for the participants or else we are kidding ourselves. The very basic question is the one which Julian Stein asked us to ask ourselves at the very beginning. "Do we ever wonder why we are working with handicapped people?" Last night, in talking with my son at about 1:00 a.m., he asked me how I got into this work. I said, "Well, when I came out of the Marine Corps, my brotner Bobby had been killed in Iwo Jima and I decided that I had to do something more worthwhile than going back to work for the Associated Press." He says, "Dad, I'm 26 years old and you never told me that before." I said, "Well, you never asked me before."

We heard Julian Stein talk about Larry, the film, and about socialization and about normalization. All those words that mean so many things to so many people. He talked about consumer involvement in rights and consumer involvement in advocacy which is so much the norm today, particularly with agencies like Easter Seals. He did say that we should remember that today's answers are not always tomorrow's answers. The changes in legislation, the changes in public attitude, and the changes in perceptions frequently result in the need to be aware that we are creating new needs and not reinventing the same old wheel.

From the keynote we went on to the facilitators whom I mentioned before. We talked about sharing work experiences. We heard from a Girl Scout representative, we heard about the liaison between Girl Scouts and Boy Scouts which could be symptomatic of any other liaison or lack of it in any community.

We talked about myths and realities. We heard Joan Kristoll tell us about some things with which she is familiar. She talked about many things as did Carl Eichstaedt. Certainly his enthusiasm was catching. I thought Carl made a very enthusiastic presentation. He told us that in the near future all children will have IEPs and that we should enjoy our lives. In the Boy Scouts we say that unless scouting is fun, it is not worthwhile. Enjoyment, I think, is something the old Jewish mothers used to say along with the chicken soup, "ENJOY." If you aren't enjoying what you are doing and if your students or classes or associates aren't enjoying it, then possibly it is a good time to take another look at your program. We have to instill that feeling in our young people as they are doing at Friendship Facilities - enjoy the scouting extra in their work and their work environment or their home environment.

The child is really the center of our program. The program isn't, the child has to be the center. Back in the middle 40's when I started working with some of the top people in this country as a relatively young person then, meeting with many of the top doctors and educators, I used to tell people that the

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doctor was not the captain of the team, it was the patient. The educator was not the captain of the team, it was the student. Coming from a young marine major in those days, that was heresy, but it has proven to be the case today. I do not want to make myself a prophet, but certainly it is the patient, it is the person who must be considered. If the person is not the center of what we are doing, then we had better take another look at our programs because sometimes agencies, I think, tend to think of the program as being the "be all and end all" and the individual possibly being an adjunct to the program. This is something that Carl told us to warn against. He talked of all kinds of recreation and recreation opportunities and vacation opportunities.

Here and there and everywhere we talked about labels; what to do with them, how to use them. We must make sure that the label is only useful and is not a putdown. It is not something that is of a negative nature.

At our banquet we learned that disability is a relative thing. We had a very excellent substitute for Dr. Betts. Dr. Toerge talked about the fact that so few people ever reach their potential and that is partly our fault, I suspect. It was Emerson who said that, "If you treat a man as he is, he will probably stay that way, but if you treat him as he could be, he will become what he could be and should be." That is what I think Dr. Toerge was sharing with us. He also said the medical profession is not always able to provide the answers. We have known for a long time that doctors, educators and ministers as well as others in the field of religion, don't have all the answers. Dr. Toerge did say something which I hope many of you will take home with you; that many doctors still need more understanding and you are the people that can help them in the learning process.

We talked about performance being the key and we have to make real efforts to make sure that people do perform. We learned that equipment is only useful if it is used. I once had a deputy who had an artificial arm and he left it in the attic. He didn't need it so he didn't use it.

We talked about bridges to the community. Tuesday John Sullivan told us about the Sons of the Desert and how he used the Laurel and Hardy films. He pointed out that socialization and recreation are a very important part of life. If we can socialize people who have never had the opportunity of being socialized, we can make their lives in the work world or the outside world much easier. He said that mainstreaming is one of the best things going in America today.

We had five speakers from Little City, from Easter Seals, from the Boy Scouts and Chicago Park District, and that wonderful little lady, Vicki Conley who beautifully expressed what they are doing at Access Living.

We have talked about flexible schedules and I have rapped about administrative announcements, but they are important and they help us get on with our other parts of being human and getting our room in order and getting a meal now and then.

Due to the weather; Rich Escutia, Jim Schommer and Neil Sol made the luncheon presentation. They did a great job. I also felt that same experience about taste buds going bad. My doctor has taken me off salt the last two weeks and everything tastes terrible. That hasn't stopped me from eating, but he has convinced me that taste buds are probably a lot better with salt. He mentioned a calcium loss promotes the bends and he wasn't talking about the bends you get from staying under water and coming up in a hurry. You have to be careful not to lose too much calcium and he said we all can slow down the process of aging and that fitness brings other benefits.

We talked about use and disuse and specific activities and individual differences and then we talked about growing old gracefully with Neil Sol. He mentioned that exercise has the ability to halt all degeneration due to age and the benefits of the body physique also include other benefits through exercise mentally, morally and physically. He did say that people my age, 64 and up or down, can take part in competitive sports and I competed along with the rest of them yesterday as we were going up and down this floor when Dotty Koelling was putting us through her paces. I didn't puff as much as I thought I would. Although I played 18 holes of golf on Saturday, walking, I found myself a little more exhausted, a little more exhilarated due to the exercise I did here for half an hour than I did the whole three hours it took me to play golf in the morning. We found out that regular exercise means quick recovery from exertion and exercise is the means of decreasing the aging process. Exercise improves the quality of life. Rich Escutia mentioned that and so did Neil Sol.

All the people from Chicago were just great. I'm not sure some of the people in Washington would have driven six miles across the Potomac in weather like this to come to a meeting in town. Many of you had to drive anywhere from 15 to 30 miles to get here and here you are staying.

Joe and Beth presented information and distributed materials on volunteer training. We heard about athletics for Seniors and we learned we could run and play for health in thirty-eight different ways in the Senior Olympics. I'm going to check into the Virginia Golden Olympics. I used to be captain of the track team at Marquette, I used to run the quarter mile. Today I don't even like to run for a streetcar. It is important to remember that the children we worked with today will be able to prolong life and thumb their noses at the calendar through active exercise.

Beth Broadway took us on a walk through our agencies. I had a hard time walking through 3,008 counties where the Boy Scouts are. That was a tiring walk I took because I operate out of my house as a volunteer chairman for the country which I am not going to be after a couple of months. Beth asked us to think about where we could use more volunteers. She asked us to see where an extra pair of eyes could help us in our facilities and our programs. I wrote my answers down. I would like to see some more people on Council Boards, on unit committees, and sponsor partner boards and among school boards and among media people and show people. I would like to see more movers and shakers in our program for Scouting although we still have quite a few of them. I would like to see more of the movers and shakers in scouting than we have, more moving and shaking in the field of the handicapped which we managed to increase over the past several years. This was partly because I set up several of these committees with them and they looked at me as a fellow peer. I take suggestions from them too, as I am sure you do.

Quo Vadis

I heard that not only did the YMCA keep open during the week and weekends, but they also work on Sunday. They have got a group down there on Sunday. At our church in Arlington, we bring over children from a school for the retarded to do all of our bulk mailing and we pay them and that way we get them used to the world of work at a relatively early age.

We heard about things from John Sullivan. We saw all his tools of the trade, his box of surprises and then we came up here and we heard thanks from our host, Rich Escutia and our lady volunteer host here. We are the hard core and I think that is pretty much the Quo Vadis.

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Chicago, Illinois
February 9-11, 1981

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CHICAGO, ILLINOIS
February 9-11, 1981

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Mainstreaming Activities For Youth

Plymouth Hilton Inn

Livonia, Michigan

February 12-13, 1982

Mainstreaming Activities For Youth
(Project MAY)

A Project to assist youth serving agencies in planning, developing, implementing, promoting and evaluating a collaborative program to mainstream handicapped youth in regular programs.

P.O. Box 1781, Longview, Washington 98632
Phone: (206) 577-0243

PROJECT DIRECTOR: GRACE D. REYNOLDS
PROJECT OFFICER: WILLIAM A. HILLMAN, JR

AGENDA
MAINSTREAMING ACTIVITIES FOR YOUTH
Plymouth Hilton Inn
14707 Northville Road
Plymouth, Michigan 48170
(313) 459-4500

February 12, 1981 - Thursday	ROOM	SESSION
8:00 a.m. - 10:00 a.m.	Foyer	Registration
8:00 a.m.	Plymouth 3	Films
		SESSION I
10:00 a.m. - 10:50 a.m.	Plymouth 3	Opening Session Introductions Keynote Address The Inclusive Mainstream Julian U. Stein, American Alliance for Health, Physical Education, Recreation and Dance (AAHPERD)
10:55 a.m. - 11:50 a.m.	Plymouth 3 A & B	Small group discussions in response to the keynote address

Facilitators	Resource
John Sevier, Boy Scouts of America	Rosemary Pulick, Mercy Center
Julian U. Stein, AAHPERD	Lynn Ruttenberg, Livonia Family Y
	Beth Shurte, High Point Cente

		SESSION II
12:00 Noon - 1:50 p.m.	Plymouth 4	Luncheon Guest Speaker - Michael Cicchella, Livonia Family YMCA

February 12, 1981 - Thursday	ROOM	SESSION III
2:00 p.m. - 2:55 p.m.	Plymouth 3 A & B	Mainstreaming: Personal Values (Manual I) Small Group Discussion Facilitators Daryl D. Jenkins, Project MAY John Sevier, Boy Scouts of America Julian U. Stein, AAHPERD Resource Margaret Oles, N.W. Assoc. for Retarded Citizens Rosemary Pulick, Mercy Center Lynn Ruttenberg, Livonia Family Y
3:00 p.m. - 3:40 p.m.	Plymouth 3	A Parent's Point of View Panel Presentation Panel: *Sylvia Clock *Francis Costner Maybelle Munn, Association for Retarded Citizens - Northwest *Lorretta O'Leary
3:50 p.m. - 5:00 p.m.	Plymouth 3 A & B	Mainstreaming: A Guide to Developing a Program (Manual II) Small Group Discussion Facilitators Daryl D. Jenkins, Project MAY John Sevier, Boy Scouts of America Julian U. Stein, AAHPERD Resource Margaret Oles, N.W. Assoc. for Retarded Citizens Rosemary Pulick, Mercy Center Lynn Ruttenberg, Livonia Family Y
5:00 p.m. - 5:30 p.m.		Break
5:00 p.m.	Plymouth 3	Films
5:30 p.m. - 6:00 p.m.	Plymouth 4	Reception - no host
		SESSION IV
6:00 p.m. - 8:30 p.m.	Plymouth 4	Dinner The Consumer Speaks John Mathey, Wayne County Intermediate School District Matt Trippe, University of Michigan

February 13, 1981 - Friday	ROOM	SESSION
8:00 a.m. - 8:45 a.m.	Plymouth 4	Continental Breakfast available for registered participants
8:00 a.m.	Plymouth 3	Films
		SESSION V
8:45 a.m. - 9:30 a.m.	Plymouth 3	Community Resources Gail Shute, Madonna College
9:30 a.m. - 10:20 a.m.		Concurrent Sessions
	Plymouth 3	The Kids on the Block - Lois Bass, Plymouth Canton Community School District
	Pool	Aquatics - Ruth Harris, University of Michigan
10:30 a.m. - 11:20 a.m.		Concurrent Sessions
	Plymouth 3	The Kids on the Block - Lois Bass, Plymouth Canton Community School District
	Pool	Aquatics - Ruth Harris, University of Michigan
11:30 a.m. - 12:15 p.m.	Plymouth 3 A & B	Mainstreaming: Your Personal Guide (Manual III)
		Small Group Discussion
		Facilitators Daryl D. Jenkins, Project MAY John Sevier, Boy Scouts of America
		Resource Margaret Oles, N.W. Assoc. for Retarded Citizens Rosemary Pulick, Mercy Center Lynn Ruttenberg, Livonia Family Y
12:30 p.m. - 3:00 p.m.	Plymouth 4	Luncheon The Handicapper - Jack Kirksey, State Representative
		Wrap Up Grace D. Reynolds, Project MAY

*Additional information not available at time of printing.

THE INCLUSIVE MAINSTREAM

by

Julian U. Stein
**American Alliance for Health, Physical Education,
Recreation and Dance (AAHPERD)**

How much of our talk about mainstreaming is from perspectives of professional providers of services rather than from vantage points of individuals with handicapping conditions? How many of our attitudes are based on expectations influenced by handicapping conditions? How much of our thinking has been influenced by categorical approaches? Labeling? Hardened categories? These are things an individual can do and these things that individual can't do? As we plan programs and placements, lack of expectation, even negative expectations influence our guidance and directions we encourage or in some cases demand of individuals with handicapping conditions. How much of what influences us has been based on disabilities rather than abilities? How much have we looked at deficiencies rather than potentials? How much have we accentuated the negative rather than the positive?

Dolly McClone retired as a physical education teacher from the Denver (Colorado) Public Schools at the age of 65 and went to Laradon Hall in Denver as director of physical education and recreation. Laradon Hall is a facility for those who function in moderately retarded and lower levels. Most of the Laradon Home population is severely and profoundly retarded. Dolly McLone very pointedly asked if problems with retarded populations were caused by their inabilities to learn, or rather from professionals' inabilities to reach and teach them!

In a film about a learning disabled boy entitled When A Boy Can't Learn, a young man is shown graduating from high school. As he is walking across the stage to receive his diploma, his counselor says in an overvoice, "If he can't learn the way you teach, then you had better start teaching the way he can learn!" A poster in Canada shows an individual in a wheel chair with the caption, "If you look at this long enough, the wheel chair disappears!"

How many of us consider Venus De Milo a double-arm amputee?

Our own attitudes, our own expectations, influence approaches we take in integrating--or segregating-- individuals with handicapping conditions into--or from--regular programs. Personally, I worked three years with retarded children before having any special education or adapted physical education courses. I didn't know all the things these youngsters couldn't do! I had not been contaminated by reading the books. When I went back to school I started reading and reviewing research and sat in classes where broad generalizations were made about lack of physical abilities or poor motor proficiencies and extremely low levels of physical fitness of mentally retarded persons. My reaction was, "Yeah, the kids' characteristics fit, but not their motor and physical proficiencies."

More important than generalizing and categorizing is asking yourself a basic question, "Why do individuals with handicapping conditions have difficulties in particular activities?" We should not try to say it is simply an inherent characteristic of retardation or inherent deficiency of someone in a wheelchair or an individual with cerebral palsy. How much of severe and profound retardation is a product of life in an institution? Several years ago national television presented a program called Larry, a true story about a young man in California who had been in a residential facility since he was one week old. Larry was diagnosed as severely and profoundly retarded. Larry had no verbal communication, no animation in his voice at all, and not only walked in an incoordinated way, but walked with a limp. A young psychologist felt that she noticed in Larry some reactions that suggested he was not as retarded as diagnosed. She was given permission to work with Larry. As it turned out, Larry was not as retarded as he was supposed to be--was not retarded at all! As Larry got into the community, he had problems. He was rolled, beaten up, and taken advantage of. But Larry felt, "That's part of life, the risk I have the right to face."

Larry not only became verbal, very verbal, but became extremely animated in his expression. He not only walked in a coordinated way, but lost his limp as well. One of the reasons that those had been his dominant characteristics initially was that he had only seen negative models, had not had opportunities to interact with a wide range of behaviors. Larry had not seen or heard individuals conversing a great deal; had only seen individuals who walked in uncoordinated ways with limps. His behavior was influenced a great deal by these individuals. As Larry got into the community, he had many other and positive models. Positive models from a variety of individuals are vital to one's growth and development. Not only do those with handicapping conditions learn and model from able-bodied persons, but it works the other way too. Able-bodied individuals learn from interacting with those possessing handicapping conditions.

Several years ago a model program was designed to integrate youngsters with handicapping conditions into regular school programs on an experimental basis in Montgomery County, Maryland. This was before The Education for All Handicapped Children Act. Five groups had to be prepared and oriented--both sets of children, both sets of parents, and the teachers. Two of these groups posed no problems--they were ready, willing and did a good job in the programs. The two groups of children were ready, willing, and able. Groups where the difficulties occurred were the three groups of adults, including both sets of parents and the teachers. The experiment was a success, in spite of the adults!

I often think of that great American philosopher, Pogo, who said, "We have discovered the enemy and it is us!" How much of inability and unwillingness to look upon integrating individuals with handicapping conditions objectively and unemotionally really rests within us? We resist accommodations necessary to incorporate some individuals with physical and motor problems into regular programs. In softball, for example, no matter what, everybody must be limited to three strikes. Why not have some individuals who get four, five, or six strikes? We have seen many programs integrated this way--it is not just individuals with handicapping conditions who get four, five, or six strikes!

Several years ago in Lansing, Michigan, a paraplegic pitched for a softball team that won the city championship in the Lansing Park and Recreation Department Softball League. He pitched off his knees! In the championship game, he not only pitched his team to victory, but he got four hits in four times at bat. The only accommodation made was when he was at bat--he was allowed a runner. This really put his team at a disadvantage since the runner had to start behind him and actually run further than someone who started to first base from the batter's box.

The Inclusive Mainstream

A question often comes up, what about teams bunting against a paraplegic pitcher? Opponents were not prohibited from bunting because this would change the character of the game for one individual. This is not the intent of making accommodations. Intent is to provide opportunities so that individuals can take part equitably and without destroying the character of the activity itself for able-bodied participants or competitors.

Daryl Jenkins made a point regarding individuality of choice. Individuals in wheelchairs have to play wheelchair basketball if they want to compete in basketball. However, to play or not to play is the right of each individual. Inclusive mainstreaming does not imply or suggest that every activity for every individual must be integrated. Inclusive mainstreaming is based on each individual's interests, needs, and abilities.

The word mainstreaming itself creates many problems because it is misinterpreted, misunderstood, and misapplied. Some people look upon mainstreaming as meaning doing away with special programs. They think it means automatically putting all individuals into regular programs regardless of their interests, needs and abilities. This is not the intent. Terminology stems from the 1971 Pennsylvania Association for Retarded Children case which introduced the zero reject concept. Zero reject means nobody is rejected from a program because of a handicapping condition. This is a normalization concept which has become the basis for nondiscrimination through Section 504 of the Rehabilitation Act (P. L. 93-112). Section 504 simply says, no one is to be discriminated against, excluded from, or denied benefits of a program because of a handicapping condition. Each individual has the right to participate in programs that are integrated even if accommodations are necessary. Accommodations can take many directions--adaptive equipment, adjusted scheduling, individualized programming, organizational and administrative changes, curricular modifications.

How can individuals with different handicapping conditions be integrated into regular aquatics programs? In a beginners' swimming class, why can't individuals who use flotation devices that are necessary for them be integrated and learn to swim right along with everyone else? Why can't they be integrated in advanced swimming classes-with or without flotation devices? Individuals preparing to compete at the international level in the Olympiad for the Physically Disabled, International Games for the Deaf, International Games for the Blind, Cerebral Palsy Games, or Special Olympics can and should be able to practice with others including able-bodied athletes preparing for similar competitions at the international level. Individuals with handicapping conditions preparing for international competitions can now use U. S. Olympic training facilities right along with able-bodied athletes. For years, in England, international level fencers preparing for the Olympiad in wheelchairs have practiced right along with the Olympic level fencers preparing for the Olympics. Some international level fencers have said that from the standpoint of pure fencing ability, individuals in wheelchairs are better than able-bodied fencers.

The motto of cross country and track teams I coached was: The difficult we do immediately; the impossible takes a little longer. This is attitude. How much of difficulties in implementing integrated programs arise because of the big deal we make of it? How much is because of specialization and specialists? In the medical profession you cannot find a general practitioner any more because a general practitioner is a specialist! How much of problems in integrating individuals into regular programs is because we have been brainwashed for years? Specialists--special education, adapted physical education, therapeutic recreation--have said, "Don't attempt to deal with persons having handicapping conditions unless you have special training, specialized environments, different equipment, different curriculum and different activities."

Now the same regular teachers and community leaders are being told, "You are a good aquatic instructor." "You are an excellent teacher." "You have a great community recreation program." "There is no reason that you cannot accommodate individuals with handicapping conditions into your programs." Regular teachers and community leaders are throwing up their hands and saying, "Wait a minute! For years I was told, 'hands off'; now you say that it is just a different way of dealing with a different type of difference."

Yes, a difference is a difference only when it makes a difference! How many of that make a difference differences have we created? The burden for changing these attitudes is on specialists--special education, adapted physical education, therapeutic recreation. New roles are created for these specialists. Needs for specialists are not eliminated--there are two more roles for specialists--working directly with severely involved individuals who need specialized and segregated attention, and serving as a resource with works, primarily with providers of services. Certainly there are individuals who today are not ready for integration into regular programs. They have physical skills and motor ability, but not the confidence, or emotional control, of social awareness to be integrated into regular programs and services. Their difficulties might come from compounding of intellectual aspects of the activity so that some type of special consideration may be necessary. Such special considerations can range from total separation to accommodating differences in regular programs. The only accommodation necessary may be pairing that individual with a buddy who becomes an internal advocate in that program for the individual with a handicapping condition; all that may be needed is an adaptive device.

It is not a matter of looking upon a group and categorically saying, here is the program, here is the approach, this is the way, this is what is going to be all things for all of these individuals. The key is individualization. We have tended to label individuals. Categorically they are mentally retarded, blind, deaf, cerebral palsied, orthopedically involved. Then we have grouped them, generally homogeneously, based on handicapping conditions. I suggest that there is more homogeniety between any categorical group of individuals with handicapping conditions as a group and the able-bodied than within that group itself; there is greater heterogenity within the group composed of individuals with handicapping conditions. Because an individual is mentally retarded does not mean he/she is motorically retarded. Because an individual happens to be in a wheelchair does not mean he/she cannot perform high levels of many activities including those in the physical, motor and sport areas.

Often special programs of all types insulted abilities, interests, maturity, experiences, and ages of participants with handicapping conditions. Physical education and recreation including adapted physical education, therapeutic recreation and adapted aquatics have not been much better! Adapted physical education has been on accreditation standards for secondary schools, colleges and universities since the mid 1950's. What went on in many of these

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adapted physical education programs would--certainly should--embarrass and shame all of us today. Activities included ring toss, rubber horseshoes, shuffleboard, chess, checkers, activities that were no way within interests and abilities of participants.

What individuals with handicapping conditions needed and could do were determined categorically. Today the approach emphasizes the individual. What are the individual's interests, needs and abilities? --focus is on ability. We need to de-emphasize and go around disability. We may have to give a disability some consideration in determining accommodations and methods, but no more so than done anyone else. We can draw a parallel from American law. In American law an individual is innocent until proven guilty. We have dealt with those with handicapping conditions as if they were guilty until they proved their innocence. They were relegated to special programs and had to fight their ways out. Unfortunately, in too many cases they never got out. Today these same individuals have the legal right to be in regular programs; any deviations from regular programs are our responsibilities to show why the individual's needs cannot be met in regular programs. To put individuals into regular programs for which they are not ready is cruel, but to keep them out of regular programs when they are ready is criminal.

This in essence is what current laws are saying.

We have to break either/or approaches--either an individual is integrated or the individual is separated. Either the individual is integrated for everything or separated for everything. We have to apply the continuum of alternative or optional placements to activities as well as to individuals. Again, this emphasizes that individuals must have choices. For example, an individual may want to be with those in wheelchairs to participate in wheelchair basketball. For square dancing the same individual may want to be in a regular group. There is no reason an individual in a wheelchair cannot square dance right along with everyone else. Every square dancing movement except one--moving sideways--can be done in a wheelchair.

This is 1981. We should be looking to 1990 and 2000 programatically. Let us not in 1981 be moving back to 1965 or to 1950. Many things being advocated today would have been great in 1965. They are not as appropriate in 1981. We must keep positive expectations, look to abilities, and involve individuals with handicapping conditions at decision and policy making levels. We must listen to what consumers-participants want.

Michigan has one of the most active consumer advocate groups--handicappers--anywhere. This group acts on conviction. They have changed the word and connotation of handicapped--handicappers signifies action and ability. They have gone contrary to international recommendations regarding changes in the international symbol for accessibility. Their feeling is that the Governor accepted international symbol for accessibility connotes passiveness and not type of action and activity they want and need. We must involve and listen to What those with handicapping conditions are saying. It is long past time that we stop imposing our wills on and forcing individuals with handicapping conditions to do what we want based on what we perceive as their needs. After all, we are all interested and concerned with providing persons with handicapping conditions greatest opportunities to be a part of the mainstream of society.

The Inclusive Mainstream

In an ancient culture there was a wise, wise man. As in all cultures, even today, the younger generation wanted to show how inept and unwise the wise man was. This group decided they would discredit the wiseman before the entire tribe by going to him and having one of them say, "In my hand I have a bird; tell me is this bird alive or dead."

If the wise man said the bird was alive, the individual would crush the bird and show the dead bird. If he said the bird was dead, the individual would simply open his hand and let the live bird fly away.

This was presented to the wise man, "In my hand I have a bird. Is that bird alive or dead?"

After a very few minutes of thought, the wise man said, "The answer to that, my son, is in your hands."

The degree to which we involve individuals with handicapping conditions, make them a part of the mainstream of society, and make least restrictive environment concepts work, rests in our hands.

PARENTS' POINT OF VIEW

by

Maybelle Munn
Northville Public Schools, Northville, Michigan

We are very pleased to be here today to share our point of view as parents. Quite often we have wished that we had an audience of professionals to listen to us because we do have a great deal of input into the lives of our children and we are concerned about their future. As parents of retarded children we have one thing in common...our handicapped children. Although we all do not share the same point of view as to how they should reach their future and fulfill their potentials, we do have one concern and that is that they be able to have the opportunity to fulfill that potential.

I would like to read to you something that I found in a communication, something that the Governor of Minnesota said when he addressed the first convention of the National Association of Retarded Citizens:

> "A human being is an individual with value that cannot be measured adequately in terms of materialism, usefulness to the state, physical fitness or mental capacity. The retarded child has the same rights that children everywhere have. He has the same right to happiness, the same right to play, the right to develop to the fullest extent within his capabilities and the right to love and affection. He has these rights for one simple reason. He is a child and we cannot discriminate against this child or deny this child the rights of other children because of one thing neither he nor his family can help, because he is retarded."

That statement was made thirty years ago. It has not changed.

The Association for Retarded Children just celebrated its 30th anniversary. I am very proud to be a part of that association. Were it not for their support, I would not be where I am today and that is not just a casual statement. They have been very helpful and supportive to me during the last fifteen years and I am proud of what the Association has been able to do. My fourteen-year-old daughter, fifteen now, (she will be very angry if I do not tell you she is fifteen) has had very few mainstreaming opportunities and I was thinking before I came here of the times and opportunities that she has had. There are not too many.

I will tell you about one experience because it is one which I think has a great deal of bearing on this conference. In the summer of 1979 Ann was able to go to the International Special Olympics at Rock Point, New York. She was one of several children from Lane County and one of ninety from the State of Michigan. It was an honor. We are very proud of her ability and her and the fact that she was chosen to go. She had to get ready for that event and we looked around for ways that she could keep training all summer because, if she was lucky, she got to swim at school once a week. In order to really be in top shape we wanted her to experience an everyday time in the pool. Through the efforts of her physical education teacher, she was able to get with the Bulldog Aquatics Club with normal children much younger than she, but who were in the process of a daily swimming program and regime. We were not sure that she could keep up this daily swimming at a pool for almost two hours every night, but we decided to risk it and see what she could do. I am proud to tell you that, for the most part, she stuck it out. She got tired at the end of those repetitive laps, but she stuck it out. At the end of that session while she had not made any friends, no one had really rejected her. One little girl was friendly to her, perhaps out of curiosity, but at least she was friendly. At the end of that session that summer before Ann went to New York, she had been able to learn some things she had not been able to get from the Special Education classes that she had taken so far. She learned to flip turn which may seem very basic to you, but to her that was quite an achievement. She had not learned that in school. She learned that by emulating all those normal children with normal abilities. She watched them for a few nights and then, before you knew it, she tried it herself. She is very agile in the water and the flip turn enabled her to save quite a few seconds on her stroke, on her speed. She also watched those other children as they did the butterfly which she had not tried to do. At that point she was able to do the crawl and the backstroke, but the butterfly was another matter so she tried to do that. My point is that this was her first opportunity to watch and emulate normal children and she responded, in time, by actually being able to do that so her exposure was very good.

Other than that, there are limited opportunities for her. She does participate in the Just Fun Club which is a social group and recreational group for handicapped children in this area. She has participated in the summer recreation program sponsored by the Parks and Recreation Department in Livonia. There is also a segregated program and she has attended Summer Camp which is a totally segregated program.

PARENTS' POINT OF VIEW

by

Frances Castner

Mainstreaming has for many years been a great interest for our family. We have had the opportunity to mainstream our daughter, Mary, who is now eighteen. At this point we can truthfully say that those years of mainstreaming were for her the most advantageous years of her educational life. I can say this with no qualification whatsoever.

Actually, you all know that mainstreaming is not new. It is being done quietly here and there all over the world. There are many negative attitudes and these are readily understood by those of us who are parents of handicapped children. We can appreciate the fears of the unknown factors. We know that those of you who work in recreational programs don't have any idea, many times, of the kinds of things that can occur. But you know, it has often occurred to me that probably you are the people that we should approach first. You are the people who would perhaps be better able to accept and to work with some of our handicapped children because of the type of environment in which you work. Your environments are somewhat less restricted and this is the kind of thing that our children respond to very well. Certainly, you are the people too, who can look at recreation programs, who can look at extracuricular activities and you can get all wound up with enthusiasm because you have seen sometimes a growth in self esteem and you know what it means to you. You have seen someone's sense of personal dignity be strengthened and you know what it means to you. You know someone's self confidence has grown, someone's willingness to try one more time and "see if I can make it."

All of these things are well known factors to you so it seems to me that you are the people who can benefit our handicapped children. We can appreciate many of the negative attitudes that you have. There are many times, as we work in the communities today, when we are going to say that it just cannot be done. Perhaps it is because we are at a peculiar stage, as you well know. We have young people coming out of institutions who have had no background and experience socially whatsoever. You are going to be asked to try to work with these people. You have people coming from schools where their backgrounds are very different. You are going to be asked to work with these. But would you keep one thing in mind, please. Think, if you will, of the ideal. Think; if we could only begin with the lower grades, if we could begin with these early age groups with whom you work. Start now, rebel!! The rest of these age levels we will pretty much have to handle as we find ourselves capable of doing so depending upon the kind of staff we have, how well educated they are to meet these problems, the types of environments with which we are working. If you keep in mind this ideal, how much it can mean to our handicapped children to grow socially, and they can only grow socially well and completely if they are competing with and working with and playing with all children.

Parents' Point of View

I am convinced of this. I have seen it happen. I know it to be true. Now this does not mean that it is not going to be a great deal of work. There is going to be much pain, many disagreements, a great deal of having to go off on your own, but it is worth it if we could only get one child to realize his self worth and to try one more time to achieve something. This is what life is all about and you people who push sports programs and working together in groups, you know this better than I do. We ask that you consider this ideal, to keep it in mind, and if you work toward it, you know what happens? It becomes a practical working principle and before you know it, there is mainstreaming. We won't even have to use the word anymore. That is the time that I am looking toward, to when we can think of education and play and opportunity without giving it any kind of a special label or any kind of a special grouping. In my opinion, this detracts, not only from our purposes, but from the actual accomplishment that we like to point to when we are all through.

Our society is fiercely competitive and often cruelly given to talking about other people. Our handicapped children are able to face some of these things. They are able to face competition, and they are able to face being called names. It takes awhile, but if on the heels of some of these "down" moments, they can achieve some of these "up" moments, this is really what makes it all worthwhile. You people are in a position to achieve some of this and to help us as parents realize what it means to bring our children into the fullness of personality and being.

PARENTS' POINT OF VIEW

by

Carol Bollman

I have been making notes and just decided to throw them all away because the preceding person said all the things I really felt like saying. You people probably have the best opportunity to make positive kinds of beings for our youngsters who are handicapped. I guess the degree of difference in handicaps seems to be one of the problems that you are having to deal with because of the need for highly developed programs for such a variety of problems. You have different age groups, you have different handicaps, you have different symptoms, so many differences.

My fourteen-year-old daughter has been in pretty much a mainstreamed educational program since she started kindergarten. As far as recreational kinds of activities, the activities were available when her mother was Brownie leader. Nobody else wants to have this kind of youngster who doesn't sit still, who doesn't keep quiet, who doesn't pay attention to the troop. Needless to say, none of the other mothers seemed to realize that their seven-year-olds really don't sit very still or be very quiet, any more so than the learning disabled youngster.

In the case of the learning disabled youngster, as he grows older and if there has been very little intervention, we almost invariably have an emotionally impaired adolescent who has fewer and fewer friendships, if any at all. That is probably one of the biggest problems that we have had to deal with as a family because this girl doesn't bring home her friends, doesn't go to visit any friends because people have called her, well, not really names, but they have identified her as being different. Yet a number of youngsters, whom she has in classes with her, are very protective of her. They do not let other children hurt her feelings as easily as they did when they first met her. The advantage of her being in the classroom is that in the high school program she is in right now there is one young lady who does not like to go to school and frequently is ill and not from any real physical problem. Kate has a tendency to think school is very important and she is always saying, "Come on, we have to go to our next class." In essence, Kate is helping this other young lady with her problem by saying, "I'm struggling through and I have just as many other kinds of problems, but if I can make it, you can make it and I'll be your friend and come along with you." You can use these youngsters to a certain extent to build relationships for other children who may not be as comfortable in a certain setting.

As I was saying about activities that have been available, I encouraged our school system, because that was the agency that was running the swimming program, to have a beginner's swimming program for handicapped youngsters who were in what was, at that time, called Type A programs. These included memory impaired, learning disabled, or whatever did not seem to fit anyplace else in the regular scheme of school. We did not have it all divided up into neat little categories. Whether that is beneficial or not, I am not really sure. Initially the idea was, "Okay, we'll do it", because I was bugging the hell out of them and I wouldn't go away from the school board meetings and I wouldn't go away from the superintendent's office, and so on. So they decided to do this swimming program. It was very successful. It lasted two summers.

Parents' Point of View

They would throw the plug at the end of the page that listed all the swimming types of programs that would be available through the summer and then they would throw in this thing at the end that said, "Special Education Swimming Program." Parents of young handicapped children are reluctant to dump their children in something that they didn't know how it was run, who taught it, or who was staffing it. What kind of credentials did these people have? We are very protective parents. We have to be because our children are subjected to situations that they cannot protect themselves from. The program failed because nobody promoted it. The classroom teacher did not know about it because no one from that department that was running the program initially went and assured the classroom teacher, the social worker, all of the people who were in that job of providing information to the parents of handicapped youngsters, that it was a good program. Everyone was busy with all his other jobs and unless somebody came and asked about the program, they probably did not have the time or the energy and by the end of the day, really did not care.

It is very important that people become aware of and understand what is going on. Information must be available so people will want to come. We promote the other kinds of activities in which we want the community to participate. We hold open meetings for different things, open houses, and so on. I recently received a flyer from Livonia YMCA in where there were all kinds of descriptions of all the other swimming programs and all the other fun Saturday activities, but there was a title for the Special Ed Program and that was all. It did not tell us anything else. I was unable to go to the open house. I did not get around to it and therefore the information was stacked on a pile of things next to the telephone. The next thing I knew it was January 28th and the program had started.

You have to remember that we are not only parents of a handicapped youngster, but are also parents of normal kids, average kids, if there is such a thing as normal. We have husbands and jobs and other things and we can not just devote our entire life to the handicapped youngster. We do miss things that we wish we had gone to, but then, so does everybody. Do not look at us from the point that, if the parent would only get the child here, we would provide the program. There are many single parents who have absolutely no way to bring their child to a program. The other situation we are looking at here is transportation.

Probably the two most important issues that need to be faced are how does the youngster get there and what is provided when he gets there. The things that I like to see are more scouting programs that are for various handicaps. I have to be somewhat bigoted in my position because my youngster is in a situation where she will have to be and will not be in a situation at age 25 to have a living condition. She will be expected to go out and earn herself a living or hopefully get married, whatever. There is a large population of young people who do not fit into beginning swimming and intermediate swimming, but they are better than Special Education beginning swimming or intermediate swimming because they have had a pool in the backyard and have had experiences in water activities, but they can't handle what you consider the regular program. From my point, we need a third alternative. We need a section of in-between special education and regular programs because we have got a large part of the children who are clumsy or whatever; not great at shooting baskets, can't kick a ball, but who can learn. However, they are never going to fit into what you call regular group activities.

PARENTS' POINT OF VIEW

by

Sylvia Clock

My son is considered severely mentally impaired although I do not think he is. I do not like those titles, but that is what we have to live with. It does not bother me to call him severely mentally impaired. He is almost sixteen and is non-verbal. He has had very few mainstreaming experiences, but he has one which I think is very important.

My son goes to a CYO Camp in the summer. So-called "normal campers" are integrated with the retarded pretty much during day-time activities. In the evenings and at meals the groups are integrated. The retarded campers room together in a cabin with their counselors. This experience is good for both groups. They learn together. My friend said that her daughter's participation with normal children taught her things like flip turns and the butterfly strokes that are not generally taught to handicapped or retarded children. The point I want to make is that retarded people have a tremendous capacity for learning, far more than other people give them credit for.

Many of the good things my son has learned in the areas of play and recreation and socialization were learned from his younger brother and his brother's normal friends. The boys do not try to teach him his ABC's or colors, but teach him how to shoot a basketball, how to dribble the ball. No one taught him this at school. He is considered advanced because he can bounce a ball, but he learned that by playing with his younger brother and his brother's friends. He learned how to go down a slide because he saw the younger children do it. He goes into the pool because the other neighborhood children do. He did not want to go into the water at Special Ed programs. However, now that we have our own pool and all the neighborhood children use it, he also goes in, even has his own way of putting his head in the water.

I am not sure how much I am in favor of mainstreaming educationally because my son's level is very low compared with others. He certainly can be mainstreamed recreationally. He can bat a ball and shoot a basket. With help, he could probably learn the fundamentals of playing basketball. Probably not competitively, but recreationally. He has learned these skills by mixing with normal people.

He has even picked up a couple of words that my normal son insists are swear words, but fortunately do not sound too much like this. He has developed a high social IQ from associating with normal people. This is the message I want to get through to you.

Our association sponsors a family picnic each summer at which we have competitive events. Normal and handicapped children compete together. Some of the fourteen or fifteen-year-old handicapped can win some of the events. One young man, about seventeen or eighteen, can run as fast and throw a softball as hard as any other seventeen or eighteen-year-old. He has never had the opportunity to play on a regular softball or hardball team. He also swims very well.

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Parents' Point of View

I am not sure that we always have to have separate segregated programs. We could include our children one or two at a time. We need to stop being overprotective of our children and learn to let them fail. Normal children fail when they try things. A handicapped child should be allowed to try. If something does not work out, we should try something else.

Maybelle Munn

The young man that Sylvia was talking about who plays basketball and baseball well and swims well participated in a Special Olympics event. He swam with all his might and won that contest fair and square. When he got out of the pool and went to get his award, there were no gold medals left so one of the volunteers (in all goodness and innocence) gave him a silver medal instead of a gold medal. He was very disappointed and he came to me and said, "I won a gold medal." I said, "Yes you did. Let's go check it out." When we went to talk with the volunteer, she told us they had run out of gold medals and said, "What's the difference, it doesn't matter to him." It did matter to him. It mattered to him very much. He had won that medal and he knew he had won it. He had achieved something for which someone had very little regard.

I just want to say in my closing remarks. "Hold our youngsters in high esteem. Expect the best of them and when they do perform, give them all the credit. Please don't patronize them." We can't support them enough. We must reach out in every way we can to offer them the opportunity to be just as you and I have had the opportunity to be.

QUESTIONS AND ANSWERS:

Question: In Girl Scouting we often will have someone with a handicap in the troop and there is always the problem of whether to put a 12-year-old girl into a Brownie troop where she may be able to function at the same level as the participants or should she be with older girls who are perhaps doing things that she couldn't do, but are at her age level.

Answer: Juniors versus Cadets. She is twelve years old and she would be at the top of the Juniors as opposed to going into Cadets. When she turned 13 she would stay in a Junior troop for an extra year. We put children in kindergarten and if they are really not ready for 1st grade, we let them stay another year. Nobody thinks too much about it. Brownies have now gone into accepting 1st graders. A bad decision folks, in Girl Scouting. I think it was terrible. Naturally, being the mother of a handicapped youngster in a troop of Brownies who are 95% normal kids, I know it is very difficult for any Brownie leader to deal with twenty-four seven-year-olds anywhere, but if you are going to reduce the troop size to where the youngster who is handicapped would be in the Juniors or say the 12-year-old girl in the Juniors, but extend the length of time. I think you need to keep them in a certain age group because they are not going to go, if they are 12, to a Brownie troop. Girls in particular go through that 9 to 12 age where they don't want to do anything, or they want to do everything and they only have two friends or they have 30 friends. They don't seem to have any happy mediums. It's one extreme or the other and possibly thinking about extending the time lines and not being too rigid about the time lines would be the easiest thing.

Comment: Definitely, children would prefer to be in a group with other children their own ages.

Sylvia: I would like to point out one thing. I mentioned earlier that we have a picnic every summer and we used to ask people for donations for prizes. We would tell them that we have participants ranging in age from two or three to adults. We would ask for something that would be an appropriate prize. We would find out that whenever anybody thought about giving us a prize for retarded persons, it was always a toy, always a toy. Our retarded teenagers are not a great deal different from normal teenagers. They may not have the book learning or the intellectual capacity to understand certain abstract ideas and things, but the girls are interested in wearing makeup and having their hair done and wearing the right kinds of clothes. They look at the right kind of magazines and they are interested in the same kinds of things. So are the boys and they don't want to be treated as children. They want to be treated as teenagers and adults. I suppose this is why we find so many segregated programs. Certainly, when you get into educable youngsters, and they are definitely in the majority, you'd be better off erring on the side of putting them with their age group because what they might not be able to do in terms of what the normal children can do does not have anything to do with intellectual ability. Certainly they would enjoy the field trips and the socialization of being with other people their age.

When we moved to this area, I attempted to get both of my girls into Scouting. The leader wanted an opportunity to meet with the troop to discuss my daughter and prepare everyone for her entering the troop. In the middle of our conversation I decided it really wasn't what I was looking for. I really didn't want this child picked apart before she got into the troop. She should be allowed to come into the troop like she was any other child on the block and decision could be made on the basis of what she could do. The leader has a right to have some information, but there was no need to go through the scrutinizing type of situation. I was really angry about the situation. It is difficult sometimes to get people to know this, but they know and they sense it right away that everybody has been informed of her condition. I can remember a circumstance when I was in high school. We had a young student and she had an epileptic seizure in the classroom. I had a cousin who had epilepsy so I was familiar with it. We had tenth graders who were terrified because nobody had the courage to come in and tell that class that this young man could possibly have a seizure here and when he did, there were so many frightened teenagers in that room because it was a "We don't tell anybody" situation. We don't have to keep it a secret to the point where when something happens, nobody knows what to do. But when you have a child who is relatively normal, a learning disabled youngster who is almost always in the mainstream efforts of the school programming, I think it is unethical to discuss her problem.

Parents' Point of View

Question: I would like to ask for some basic information about the leader. I approached the leader sitting down with the girls in the troop and telling about this person who was going to enter their troop rather than allowing the girls to make their own decisions and then maybe even ask the new girl into the troop. If you have a child who moves in from Brooklyn to Kansas City, first off you have a different kind of conversation going because of the Eastern dialect. Kids are going to giggle and say, "You talk funny." So why are we going in where no one would even say anything.

Question: So what you are saying is the easiest transition would be to have the individual involved with the group and let them carry it.

Answer: With some support. Inform the leader of the circumstance. I think it is the responsibility of the parent, especially when we are dealing with a volunteer organization such as Girl Scouts, to bring to the attention of the leader what specific problems may come up as a working volunteer agency. I cannot train all of my volunteers to deal with all the various kinds of handicaps and disabilities that they may come in contact with so I think a certain amount of responsibility has to lie on the parents.

Sylvia: I am saying that the leader doesn't go back to a regular meeting and say, "Listen, I want you guys to come to the next meeting because I am going to have a discussion with my troop and tell them all about her." This is what has happened and I just feel that it is unfortunate that there are so few groups available for any kind of handicapped youngster to go into whether they are markedly retarded, physically handicapped, severely mentally impaired. We have little groups of Girl Scouts who are handicapped in one area and another Girl Scout troop in another area several miles apart. I am saying, why do we have to go those miles, why does the leader have to make a point to talk to her troop? Now if it is a situation where there is physical impairment and it is Brownies, I think then you have to prepare these girls to a certain extent that there is going to be a new girl in their troop and she is on crutches, but you don't have to go into a five-year history of the child. I don't know that even the leader has to have all that kind of information. If a parent wants to volunteer it, that's all right.

Question: I would really like to know. When you voiced your opinion about the girls not knowing what the disability is, what was the response of the leader?

Answer: She felt that it was her responsibility to tell the girls because it was a very close-knit troop of a very few cadet girls of that age group so they didn't even know if they wanted to take another girl into the troop. This was like January and they had already made plans, etc.

Comment: The problem does not lie with Girl Scouts.

Answer: No, right, in that situation. But I am saying this is an example of a circumstance that can happen and you know, when you do training sessions, these are the kinds of things I hope you would bring up to the leaders and let them know that there are more and more handicapped youngsters being mainstreamed into the scouting activities and hopefully there will be local kinds of troops instead of separate troops for the handicapped. They live in the neighborhood, yet they are shipped 20 miles to be able to participate in Scouts or go to a swimming program. They may end up going to the same local high school or the same elementary school that the other children in their neighborhood attend. Why is it necessary for our handicapped youngsters to have to travel or be segregated in areas that are far removed from the typical community in which we live?

Comment: We had that. Our daughter has participated in many different swimming opportunities for the handicapped and always the problem was finding a pool and it is usually way out twenty miles in one direction and twenty miles in the other while we live in the backyard of the high school right next to the pool. It is an unfair thing that we always have to travel so far to find services.

ADAPTIVE AQUATICS

by

Connie O'Neil
American Red Cross

Adaptive aquatics. Just from the name adaptive you can almost make your own definition of what it is. Adapting your methods, adapting your attitudes, adapting your structure, adapting equipment - that is what adaptive aquatics is. I have thrown this question up to several people who are interested in becoming instructors. I received one really good feedback that told me what adaptive aquatics is all about. It was a good learning experience for me.

A young man who was about 14 or 15 years old responded that it is mobility - mobility for all. It is freedom of movement in the water. That is what aquatics is all about. Many times we have found ourselves just floating motionless, feeling the sensation of the water. That is mobility. It is a freedom of moving in the water.

I always like to start out with a description of adaptive aquatics to get you thinking in terms of what it is. It is locomotion. It is support in water. I want to relate another experience about this same young man. I was involved previously with the Detroit Recreation Department. This young man taught me many things about adaptive aquatics. I was really considered a raw beginner at that time. I was a Physical Education major and I was used to vigorous activity and all kinds of physical fitness things and I happened to work during what they called handicapped swim. It was three hours set aside for individuals with handicaps to come in and swim some laps. Most of the people who attended that session really didn't need to be there, they mainstreamed. They needed to be coming into regular adult sessions. They were there mainly because the pool was empty.

This fourteen-year-old young man taught me everything. I could watch him. He had no arms, no legs. The first time I saw Jimmy come into the pool I thought to myself, "Where is the rescue pole. Well, he's not going to be able to grab onto the rescue pole if he goes under and what good is that going to do?" I was really scared, really nervous. He knew what he was doing. He got off the wheelchair by himself, jumped into the water. It was an amazing sight to see. I got to know Jimmy after a few sessions. He was in there doing lengths. I could watch him move through the water. That is mobility. He had no legs whatsoever, but had half of his upper arm. He would use a dolphin-like movement with his body. He floated very easily and rotated his arms in a circle.

One day Jimmy was busy working out, doing his laps, getting ready for wheelchair games. He was a competitive swimmer and he said to me, "Connie, can you come here for a minute, help me out with a stroke." I said, "Sure, Jimmy", meaning very little. He said, "I would really like to learn the breaststroke. I would like to swim 25 yards breast stroke in the wheelchair games." I was so embarrassed. I scratched my head. I said, "I'll show you how I do it. I'll get in the water, you watch me and then we'll try and figure out what type motion you can accomplish to achieve your breaststroke movement." He didn't do breaststroke very well. He realized it was not one of his best strokes, but he did it and he could do it for a length. He did come in with first place. He taught me a great deal about preconceived notions that we have about what we can learn and what we can't learn.

So many things go on between students and instructors, so many strong emotional things that at times are achieved through working with individuals that are disabled. It is only because the disabled person possibly needs some assistance with learning to swim, but I am there as an instructor because I get so much out of it, I really do. I have learned so much and I think that we all look at the programs in terms of our learning. We can provide the program. We can do all these things for persons with disabilities, but they are the ones who are teaching us. They are the ones who really have something to offer.

The general overall values of swimming. So many people the last few days have been talking about recreational opportunities. How many of you love to swim? Why? Why do you like to swim? It is enjoyable, it feels good, especially when it is warm. Unless you like to swim hard, then you like it cold. Why else do we like to swim? It builds muscles. It is fun. It is socialization. There are many values. The film this morning basically talked about our three favorite values which you will find on the front cover of this Physical Education and Recreational Textbook. These values are psychological, social, and physiological and they are all perfect. That is why we all swim and that is why the disabled should be swimming.

I believe that the disabled person can gain so much from swimming. Swimming gives a person the opportunity, no matter what his age is, to get into the water. There is really no pace limitation if the instructor doesn't set any. A person can progress at his own speed. He can learn to float on his stomach. He can learn to float on his back. There really shouldn't be anybody saying that within two days now, a person should go under the water, learn how to hold his breath, blow bubbles. That is what adaptive aquatics is about.

Another special value of swimming for individuals who have disabilities is the idea that they can perform unassisted. That has been brought out several times. When a child gets out of that wheelchair, it is a good feeling just to be able to get out of the wheelchair and then into something and not to have to worry about someone holding him up or somebody being there by his side to assist. He can get into the water and if it is needed, put a life jacket on him and he can move unassisted. It is locomotion, an independent feeling. Swimming is one of those sports that is a lifetime sport. Once swimming is learned, it is something one can do for his whole life. It is also one of the sports that uses the most muscles in the body. Swimming evades the limitations of gravity. On land gravity is working against a person, the muscles continually work against gravity. In the water, all of a sudden limitations disappear. A person is able to move his joints and have more flexibility or he can work towards gaining more flexibility, more agility. It also takes less strength. Somebody on his back in a life jacket might be able to move himself in the water merely by splashing. Just one motion of his arm, one little flap of the hand might provide locomotion for him. That has to be exciting. That is the only movement they can do. That is locomotion. That is really movement.

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Another thing to remember is that swimming is cheap. A person can go almost anywhere and it will cost him fifty cents or a dollar.

Swimming has values for all of us, not only the disabled, but for each and every one of us. With any adaptive aquatic program, I really feel the emphasis and the key to ultimate success is the instructor and the relationships that develop between the instructor and the student and between the student and other students. It was very interesting.

I had a good learning experience the other day when I listened to some of the parents talk. I have had a preconceived notion that what would be a good thing to do would be to take our students and tell them all about the individual. I realized yesterday that that was really harmful. Now I think the role of the instructor is one that when all of the students come into the class, the instructor is the one who has the power, who has the control over what is going to happen. If names start being called, then you have to do something, but I think it would really be a great experience just to see a natural relationship develop between the students. The instructor is the person who really is the key, the real focus in terms of having a really good program. Many qualities go into making an instructor what he or she really needs to be and what he or she should be.

Empathy. You have to have an understanding. You have to put yourself in the shoes of the child. What does it feel like, what is it going to be like in the water for him? I have to close my eyes and go in the water myself so I can get some idea of what it is going to feel like. I need to strap my arms up and my legs up. What does it feel like to walk with one leg? The instructor must do that and must provide these experiences for the other students. The other students must really see and feel what it is like to be blind, to see what it is like not to be able to hear, to listen to the teacher explain what to do. We need to provide these experiences for our students. You will get these experiences today.

We also need to plan for successful experiences. There was a study back in 1971 with some physically disabled individuals which found, from computer studies, that these individuals definitely have some emotional instabilities, definitely exhibited some inferiority complexes. Why? It was not because of their disability. Their disability wasn't a problem at all. The most important factor was they found that it was the feelings, the pressures put on them by their parents, by their peers, the emotional climate. Those are the things that really influence those persons, their feelings about themselves, their self image. In the classroom, in the swimming pool, in the environment that we are dealing with; it is the parents, the teachers, the peers who are going to influence how that child is going to feel about himself.

I think that, as instructors, we need to be knowledgeable about seizures, about the different disabilities, about some of the complications that may be caused by some of the things that we do. We need a little bit of timing and a little background experience. We build that, do some reading. We should take advantage of the training that is available. The Red Cross does provide training in their instructor programs. Water Safety Instructors who would like to learn a little bit more about adaptive aquatics can take the course that will be offered in the June Water Safety School. Also, call the local Red Cross Office and find out when local community programs are offered. A person does not have to be a Water Safety Instructor, but anyone interested in knowing something about different disabilities and effects in the water can also attend the class. No one will be refused. One may not become certified as an instructor, but the learning experiences will be greatly expanded.

When I talked about instructor qualities, I didn't really talk too much about student needs, and so on. I think some of the information in the notebook that has been provided about the stimulation of activities, about utilizing our own needs and looking at our students' needs are all really important.

THE HANDICAPPER

by

Representative Jack Kirksey
Livoinia, Michigan

Let me start out with a few statistics dealing with handicapped children and people of other age groups in the state of Michigan; those whom the state of Michigan, under law, takes some responsibility to educate or provide with special services. I have only records from 1979 here. I'll leave it here so you can see it later.

Mentally Impaired	32,000
Emotionally Impaired	16,000
Learning Disabled	38,000
Hearing Impaired	3,300
Visually Impaired	1,200
Physically and Otherwise Health Impaired	4,700
Severely Multiply Impaired	1,700
Homebound and Hospitalized	1,200
Speech and Language Impaired	60,000
Approximate Total	161,000

I am sharing this with you only from the standpoint that perhaps this sets some stage for the numbers of people who are officially registered individuals with the State of Michigan. Michigan, primarily through the Department of Education, has been attempting to find ways where they might save some money. They are not trying to save some money, but millions of dollars. Some time in the next three or four months it will be necessary for the state of Michigan to cut back more in addition to the $1,100,000,000 cut that has already occurred in the budget items. Most of these cuts have curtailed services to a degree.

Last year the state of Michigan cut back $1,100,000,000. They will not be cutting back an additional $125,000,000 at the state level and $125,000,000 locally if the government tax plan is adopted by the legislature and confirmed by a vote of the people.

If the Governor's tax plan does not become a reality, it will be someone else's tax plan or a modification of the Governor's tax plan. The only thing that we can be sure of now is that there will be a reduction in taxes occurring in the State of Michigan.

That is the good news. The bad news is how this tax cut will be accomplished and what critical services are cut back versus those that were not essential to begin with and were part of the great duplication that occurs in government and the waste that occurs when approximately ten billion dollars cash flow annually is being administered. There is bound to be slippage. I am sure that many of those present have had a tax proposal of this type in their states. We had a politician who was attempting to cut property taxes about 50%. Whether you supported him or will support him in the future or someone like him, there is waste in government and the closer you get to it, the more that you can document that that occurs. We are not wasting 50¢ on a dollar. If we were, rather than change the typewriter ribbon, we would throw the machine away and replace it with a new one. But there is waste.

Any kind of tax cut is going to be a visible kind of cut a[illegible] I think it is extremely important that people like us get involved. There are ways to get involved and being involved does make the difference. When you get involved, it is what you say, when you say it, who you say it to that can make the difference. An example of this were some State Police lobbymen. When we were doing some implementing of their collective bargaining type, every State Policeman in Michigan, I think, took the day off. They stood in the gallery of the house, all in uniform with their side arms on, all looking down at us. Had they been there a month or so before, their appearance would have made some difference, however, their appearance on that particular day only made people uncomfortable. The die was cast and what was going to occur was going to occur.

There are a number of ways that you can find out what is happening, when it is happening and timing your involvement in such a way that you can provide some input. One of the reasons that this is important is that to assume that those people who represent you in government understand the problem is a false assumption. The people who came to Lansing the day that I was sworn in about three and a half years ago cautioned me that I would become very disappointed about what is going to happen here, but I should remember that everyone here represents and is representative of the people who sent them here. I thought that was a self evident truth, but when things really get discouraging, I start thinking about that up there and that is true.

It has been my salvation that, regardless of how differently people come at things up here than I might come at them, when I stop to think about it, there is a very obvious reason why they are coming at it that way. Each person up here has his own screen of values. Each person also has his own background; some have less than a high school education, some have a high school education, some have college. We all have different levels of formal training and different levels of experiential background. Once there was a large group of attorneys, now educators are the largest group. There is a tremendous mixture of people so if you assume they understand your problem and give it the same priority that you give it, you have made a huge mistake because that is not true. No matter how good a concept is and in spite of how important the problem is, how critical the issue is, the very best ideas have failed for lack of 56 votes in the House and the very worst ideas have flown for the same reason.

It comes down to a very basic selfish kind of thing which says, "What is in it for me," and the collective 'me' in that sentence is "And the people that I represent." If it is not good for my district, most often I vote against it and work against it. There are times when an issue is so overriding that that is not true. We are very provincial in our thinking. We are not statesman-like in our actions. We do some horse trading. The basic thing is that you only have so much to trade and you have got to convince people that there is something in it for them. In the Senate some of you have to find nineteen others. On some issues, when it goes beyond a simple majority, the numbers change. That is basically the concept that I want to share with you. But if you have to, as succinctly as you can, as adroitly as you can, address the issue and provide a reason for that individual to really work in your behalf and in behalf of the people that you represent and care for, or great things are not going to happen. Probably the next restrictive part of the process is that when it all eventually equates to a dollar sign, then the going gets very tough because the size of the pie is shrinking at a time when the needs are expanding tremendously.

The state of Michigan at this time, for all practical purposes, is bankrupt. We are not in a recession at all. We are in a depression. If you travel around states, and I know you have, the rest of the United States is facing hard times, but some of them to such a mild degree that they hardly notice the difference. Jobs are there. They are building buildings, people are active, etc. In the state of Michigan we have approximately, at this time, you have to think about this particular statistic, one in five people in the labor force who are not working. If you read the paper, you say, "No, that's high because it should be roughly 14% not 20%." All they are reporting are those people that are looking for work. They are not reporting another 6% or so who are no longer looking for work, but who are part of the work force.

When you take that many people out of productive posture, then you obviously have a real problem. Of this group of approximately 20% now, many of those people are not the hard core group that have relied on state and federally funded support all of their lives. We have people who as individuals and as families and their families before them, have never ever leaned toward public support. The rolls are going up. In 1975, which was sort of a bench mark for the state, a very bad time; the highest number of people applying for assistance in a given month was approximately 10,000. We have had a number of months where we have exceeded 18,000 people. If we talk about the tri-county area, then we are talking about a tremendously different problem. It is a disaster on top of disaster because we are talking about averaging out across the state and if we would look at the tri-county, the information is so discouraging that it is terrible.

What does that have to do with a conference of this type? It is only to try to reinforce the concept. You are in competition for those dollars with everyone else. People aren't working. They aren't paying sales tax, they are paying less income tax, they are delinquent on their property taxes. The whole business of transportation is a different category. People are not driving as much with the high price of fuel. Every category of taxes in the state of Michigan is dramatically down and not just adjusting merely to inflation, but historically low levels of income for the state at a time when we have astronomical outfall of dollars. So this is a bad time. It is a time where the legislators and the Governor and anyone else, even if we were to just throw every caution to the winds and vote in new taxes and say we will do this, we will do that and somehow or other we will meet the needs of everyone until things get better (which should be about two and a half to three years from now by best predictions, I think), the revolt that is going to come anyhow in taxes would be sooner and in a more vehement kind of way. The people will not stand for it. They are going to settle for absolutely nothing less than a dramatic tax cut of some type. If the government does it for them, they'll accept it and grumble because somehow or other we could have done more. If Mr. Teisch or someone else comes along, they will cheer him and he will become the next governor of the state. One way or another, taxes are going to happen. What has to be done is an establishment of priorities so that when things really get going rough, the appropriations process has to create some kind of closure which will take place toward the end of March or April of this year. You have to be as close to those people who are in the decision making process as possible so that you can say, "Wait a minute on that particular item, that is too big a cut," or "It shouldn't have been cut" or, "We have to add a little bit." That kind of process still works because you are working within the amounts of money within that shrinking pie and it is amazing what things are funded and what things are not funded in the priority process. By all means, do attempt to get as close as you can on that.

Let me talk just a little bit on what the Department of Education is doing in this. The Educational end of it is going to have a very obvious impact, I think, on all of you, at least within this state. There are contemplated changes and there has been no agreement on them, but these are some that seem to be emerging as very possible. One would be to eliminate the special reimbursement for special education summer school programs to local school districts. It means that the local school districts would have to absorb the costs that are there or if there is any kind of a fee arrangement, which there is in some instances, they would have to charge more, and so on. Also, they are looking more closely at third party payments and this is something that should have been explored more than it has been in the past. The money in many instances is there. It isn't used so you will see more third-party payments now creep into the picture. Non-residents, perhaps, who have more of a break now than they would have in other states, will start paying more if these recommendations go through. There was a recommendation made which was not accepted and that was to eliminate any services from the 0 to 2 age category. That has been put aside and they are considering within the schools themselves, changing the student teacher ratio in special education, increasing it primarily by the removal of reimbursement for aides. That, of course, is part of what is being suggested. They have to come to the legislature with those suggestions and do what they can to convince certain people that certain things should be adopted.

The other big one that I have not touched on is to reduce the number, the mandatory number of minimum days for special education programs across the whole spectrum, from the current level to something less than that so that you would have fewer days in school. That is something that is a state kind of thing. It is part of the school code and is very likely tied to legislative action. The local education will continue to have the perogatives unless things are totally restructured in determining the curriculum schedules of the instructors, the school calendar, the text materials used, teacher-pupil ratios within the guidelines. There is always some flexibility in promotion and graduation standards. The State will decide the minimum number of days, will determine the special education program, building, health and safety requirements, and supervise teacher tenure. That is the state end of it.

What you are looking at when we are looking at funding, of course are categorical grants. The rules in categorical grants are being changed. School telling you anything, but as an example in response to your question, we have a family in Livonia who have a child who is severely ill with a rare disease. The youngster is around 11 years old and will probably pass away when he is around 13. It is a very disabling disease, takes almost constant care and the care was not available through the state because the family chose to keep the child at home. The child has never been institutionalized and the rules were such that it would have cost the state a fortune to provide 24 hour care for this child. The impact on the family financially, emotionally and physically has been just tremendous. But they chose to do this and it took approximately three months, working with my office, to get the state to pay for the treatment and to put a nurse into that home. That child would not have appeared in a figure and now that child does so you know there are a number of students and individuals who are handicapped and would not appear in these figures.

Question: What kind of service cuts are there going to be?

Answer: It is too soon to tell and I will get back with you when it becomes a little more definitive than it is now. The problem with sharing anything - the list I shared with you I shared primarily to give some flavor as to what was happening in education, some of which will become reality and some of which will not. But the news is so bad that I think sometimes if we could say like this or that might go, and it would turn out to be a prediction that happily did not reach duration.

Question: Do you see the role of the private agencies, such as those represented here, becoming more important because of the private instead of public monies?

Answer: Absolutely, and as the public service is pulled back, there is going to be more and more burden on private agencies.

Well, I would hope that this kind of syndrome would occur and that would be one where if there is the tax break going to occur, I really think that certain things might intervene. The public is going to demand that their property taxes are either controlled or dramatically reduced. When that happens I think it will set the stage for private agencies and people who have special interests to then go to the sources of funding that are available in any community with the entry being that there is a control on the taxes, there has been a reduction or there is some guarantee that they will no longer continue to escalate out of control and that by that action, certain needs on the conscience of society have been created. This is the kind of special pleas you are making for some kind of direct contribution to the citizens, not to put the burden on the Y's, the Rotaries, the Kiwanians, the Lions, etc., where you do have the business people. The dollars are there in most communities, not all, but there have been some very unusually successful fund raisings that have occurred under circumstances far more severe than that.

systems thought at one time that they would be in some type of heaven if they got out of the formula. They thought they would be rich enough to fund everything from the local without depending on the state. It would be the best of both worlds. They would control all the local governments. They would call most of the shots themselves. Now they find that the state is changing the rules. They also would continue to get the categorical aids, special aids at full value even though they were out of formula and so they were eagerly looking at that time when they would be rich enough to be out of formula. Now the state is saying that rather than giving full categorical aid, what they are going to do is reduce the amount of categorical aid by what would have happened to a school if it was in formula and all the revenues would be reduced by the state. So, rather than getting a full shot at something and some special education program, the formula now is the full shot minus 30% and so your funding is, it is recommended at this point, at about the 70% level.

The other change in thinking is that things will be paid for on a cost basis. It sounds like good news. The program is going to cost the system $20,000 so the State reimburses them $20,000. That is not all good news because there will always be a dispute over what the cost of the program happens to actually be and the State will renege, as it does many times, and it will say, "Well, we'd like to pay $20,000, but the formula this year is 76% and so it is going to be 76% of $20,000. There are great problems when you start talking actual cost rather than some guarantee under a formula where, although there is some manipulation, the manipulation is more in your favor than under direct cost types of things.

What I have attempted to do is talk a little bit about the direction the State of Michigan is going and why it happens to be going in that direction. I think we all realize that much of what is occurring is going to occur and we cannot put the blame on any one area. Much of what happened has happened federally because of a number of situations virtually impossible to control, the price of oil and this type of thing. We are much at the mercy of what has happened at a national level. We are much at the mercy of what is happening in an inflationary spiral and the high unemployment rate in the state of Michigan. We are in a dilemma and my best advice to you today is that things are bad, as you know. I was trying maybe to give you some specifics and to give you the admonition to stay close to those people that you personally work with who are responsible to you so that you can provide the background and the input at a time that it will make the difference. It really does make the difference. The illusion that we are bombarded by thousands of letters and thousands of phone calls is a false one. On a given issue, if it is not one where the mail has been promoted artificially, we may get six or seven letters on a given topic. Keep the letters short, get to the essence of the problems, provide a little background and what you would recommend as a solution to the problem if it is something of an issue solution rather than strictly dollars. If it is dollars, explain what the program needs to survive in your area.

Question:	In your statement you mentioned 161,000 in terms of disabled people in the state and you indicated they are registered. What do you mean by that?
Answer:	Actually, it means that their names appear somewhere on state rolls as needing assistance from the state. And there are others, you have others. You know that this is your business and I am not

The Handicapper

I think the good news to the people is we have capped a runaway money problem. However, we have created some social needs as a result of that. This is just a personal perception, but by and large, people have a way of gravitating to taking care of their own. What they don't want to do (if we were espousing philosophy, we would all say we want to) but they don't really want to take care of everyone else.

Do you see what I am saying? Livonia, about four or five years ago, was the highest per capita income city over 100,000 in the entire United States. That does not mean that we were a super rich community, it meant practically everybody in the household was working at that time. Now that situation has changed, but in a relative kind of way. We still are relatively a growing community and if you can say to the people that we are not asking them to send all of their tax dollars to Lansing or to Washington and then get back a far smaller percentage than they should get back....

What we are saying is that they now have Johnny Jones and Mary Smith who need help. They are identifiable. You know them. They are neighbors and the contributed dollar help stays here. I think that we may see, by necessity, that happening.

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PLYMOUTH, MICHIGAN
February 12-13, 1981

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MAINSTREAMING ACTIVITIES FOR YOUTH (MAY) NETWORK MOVES AHEAD ! ! !

The Project MAY collaborating agencies have a membership of approximately 50,000,000 persons. These agencies plus over 100 resource support groups as well as training events have made it possible for us to reach many millions of persons. In addition, television coverage, newspaper coverage and special newsletters have carried information about Mainstreaming Activities for Youth around the world.

The MAY network thrust will continue. The work will be co-ordinated by the Office of Special Populations, a field office of the YMCA of the USA. Funding will limit the extent of the work.

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